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**Qualitative research among most at risk  
populations for TB and HIV in USAID  
Dialogue for HIV and TB Project pilot sites in  
Uzbekistan**

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## GLOSSARY AND ABBREVIATIONS

ART	Antiretroviral therapy
Codacet/‘crocodile’	Injection drug made by PWID from over-the-counter pharmacy products
DOTS	Directly Observed Treatment, Short-course
SW	Sex worker
FGD	Focus-group discussion
FGD-SWs-HIVt-F-30	Female participant of an FGD with SWs devoted to the HIV topic, aged 30*
FGD-PWIDs-HIVt-M-24	Male participant of an FGD with PWIDs devoted to the HIV topic, aged 24*
F-PLWH+TB-23	Female living with HIV and diagnosed with TB, aged 23*
F	Female
HIV	Human immunodeficiency virus
HIVt	HIV topic discussed at an FGD
IDI	In-depth interview
ID	Injection drug
PWID	People who inject drugs
IGP	HIV and TB infected groups of population
Informants	MARPs representatives, FGD participants, and in-depth interview respondents
KVD	STI clinic
Mahalla	A neighborhood self-government body, or a neighborhood community itself
M	Male
ND	Narcological dispensary
PLWH	People living with HIV
PLWH+TB	People living with HIV and tuberculosis
PLTB	People living with TB
PPD	Personal STD protection device ( <i>condom</i> )
Soum	Uzbek national currency; the Central Bank US dollar exchange rate was 1,900 Soums, the ‘black market’ rate was 2,850 Soums.
TB	Tuberculosis
TBPC	TB prophylactic centre
TBt	TB topic discussed at an FGD
TPs	Rayon Trust Points
TORCH	Toxoplasmosis / <i>Toxoplasma gondii</i> , Other infections, Rubella, Cytomegalovirus, Herpes simplex virus-2
VCT	Voluntary counseling and testing
MARPs	Most at risk population, population with high risks of STD, TB and HIV infection, including PWID, SWs and their clients.

*\*The abbreviations for FGD participants placed after quotations mean the 2011 survey; before quotations the 2012 survey.*

## SUMMARY

The ‘*Expert-fikri*’ Center for Social and Marketing Research was assigned with conducting the survey ‘Knowledge, Attitudes and Behavioral Practices of MARPs towards HIV and TB’ in Tashkent, within the frames of the USAID Dialogue on HIV and TB Project (*further: Dialogue Project*).

The Report below presents comparative results of the studies conducted in the city of Tashkent with MARPs, PLWH and PLTB in June-July of 2011 and 2012. For the description of the survey methodology, see Attachment *Technical Report*.

## ACKNOWLEDGEMENTS

The authors of the Report are thankful to the representatives of the Dialogue Project for the honor and credit placed in our company to conduct this survey important for MARPs and the society, on the whole.

Especially we would like to thank the outreach workers of Dialogue Project Alexander Trotsenko, Yelena Smirnova, Jakhangir Umarov, Viktor Kim, Valery Chekmenov, and others, for their valuable assistance in involving MARPs into the survey, as well as the representatives of these MARPs themselves for their honest opinions since they realized the importance of their participation and the results of the survey.

We cannot cite the informants’ names since we are obliged to keep the confidentiality of their voluntary participation in this survey.

## BACKGROUND

Starting with 1997, USAID has been focusing significant effort and resources trying to curb the spread of the HIV and TB epidemics in Central Asian countries – Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan. These countries have approved and have been implementing governmental programs aimed at controlling HIV/AIDS and TB spread, sponsored by international donors, – such as USAID, Centers for Disease Control and Prevention (CDC), World Health Organization (WHO), Global Fund to Fight HIV/AIDS, TB and Malaria, etc.

These national programs aimed at solving the HIV and TB problems, involve the population, including MARPs, namely:

- people who inject drugs
- sex workers;
- people living with HIV and TB.

Taking into consideration that the HIV/TB combination is one of the increasing risk factors for MARPs, the Dialogue Project was specifically designed to target populations most at risk of HIV and TB infection.

The results of the survey will be used for the review of the National Strategy for Communication, in development of information programs on TB and HIV among most at risk population (MARPs), as well as in development of information-and-educational materials.

## SURVEY GOALS, QUESTIONS AND EXPECTED RESULTS

**The goal of the survey** is to evaluate, and present a comparative analytical report on MARPs knowledge, attitudes, behavioral practices and services received related to TB and HIV. **The target group:** groups of SWs, PWID, PLWH and PLWH diagnosed with TB.

### **The survey questions:**

What are the knowledge, attitudes and behavioral practices of the groups of the population vulnerable to TB?

What are the knowledge, attitudes and behavioral practices of the groups of the population vulnerable to HIV?

What are the knowledge, attitudes and obstacles to receiving services and assistance needed by MARPs diagnosed with HIV and TB?

### **Expected results:**

We expect that during the survey there will be determined a number of strategies based on informants' needs and recommendations, namely:

- a strategy of teaching early care seeking for HIV and TB;
- a strategy for improving access to medical assistance for diagnostics and treatment of HIV and TB.

The results of the survey have been based on perceptions, opinions, statements and experience of the informants.

This Report and further materials refer to the results of the survey that could conditionally be generalized to the MARPs of Tashkent city only.

## **CONCLUSIONS AND RECOMMENDATIONS**

The obtained data allow us to state the following:

1. More than 10 years of activities of previous joint programs and projects launched by international and national organizations aimed at curbing the HIV and TB risks for MARPs have significantly affected domestic health facilities and some of the still functioning NGOs, which makes it possible to continue the implementation of prevention programs in the country and render the set of accessible services for MARPs, including information, psychological, health and social services.
2. In 2012, the informants representing MARPs mentioned a significant improvement in the accessibility and quality of services provided by outreach workers, the AIDS Center, TPs, family polyclinics, – in particular, an increase in VCT services offered and a higher demand for VCT, a better quality of information services, treatment, psychological and financial support, a decrease in stigmatization and discrimination, a better access to free syringes, condoms, alcohol wipes.
3. There can be seen an evident trend of overcoming stigmatization and discrimination of people living with HIV and TB (however, not of PWID and SWs) as a result of the improved quality of information and educational programs introduced at educational institutions and health facilities, as well as of the increasing number of people in social networks showing understanding and tolerance towards people infected with HIV and TB (family members, relatives, neighbors, co-workers, etc.). Another factor that helped to reduce stigmatization and discrimination was the position of different religious organizations.
4. In spite of the above mentioned achievements, the informants of the 2012 survey mentioned the following trends and risks which, they believe, pose a threat to the society:
  - The increase of the number of PWID among youth. Before 2011, the following interrelated processes could be observed: a) the reduction of heroin and opioids supply in the drug market; b) a drop in the number of PWID and SWs among teens and youth; c) involvement of PWID into the

substitutive therapy programs (cancelled afterwards). In 2012, there could be seen an increase in the number of 'Codacet' users among young PWID. These new cohorts of young people are quite unaware of the HIV and TB risks due to poor information work and the lack of involvement with NGOs' and TPs' activities.

- An increase in the number of PLWH and PLTB (smear-negative or smear-positive) not only in the service sector (chefs, waitresses, dishwashers, salespeople, etc.), but also among other professions, – e.g. business people.
- A drop in the number of NGOs and their projects, as well as the lack of TPs, or their remoteness, or location not convenient for visiting. MARPs mentioned the lack of TPs in a number of polyclinics.
- The informants mentioned the lack or insufficient amount of medicines for ART and treatment of PLTB as a result of the increased demand for services at health facilities after receiving services from AIDS Centers, TPs and outreach workers.

### **MARPs, PLWH and PLTB Knowledge and Attitudes**

1. Both in 2011 and 2012, the knowledge on HIV and TB was being introduced both among common groups of population and among MARPs by educational (from schools up to universities) and health facilities (AIDS Centers, family polyclinics and TPs). On the whole, this knowledge has been improved; but still required more attention to be paid to the risk groups who would avoid TPs being unaware of the accessibility and confidentiality of their services.
2. Before 2011, the knowledge on HIV and TB, and services provided by TPs was not quite good among the MARPs who were trying to avoid these facilities fearing the results of diagnostics, loss of confidentiality and poor quality of consultation services (MARPs were in most cases being frightened rather than informed). Starting with 2011, as stated by the MARPs, the accessibility of knowledge on HIV and TB, as well as the quality of all kinds of services has significantly improved at polyclinics, maternity homes, hospitals, TPs and AIDS Centers.
3. The knowledge and attitudes of MARPs –youth – are not quite good, as well as their involvement with outreach workers' activities, which can be explained by the rotation of generations, renewal of MARPs, the desire of young people to avoid strangers' attention, as well as by distrust of services provided by health facilities due to the lack of knowledge on their accessibility and confidentiality. MARPs of these teens know very well some symptoms or their diseases, even better – the modes of transmission and prevention methods, however, very few know about the places where they could seek VCT, and even less of them have had any experience of receiving VCT and consequent services.
4. PLTB and PLWH have full and comprehensive knowledge of their diseases, the prevention methods, treatment procedures and experience, as well as knowledge of how to prevent other people from infection, and they are implementing their knowledge in practice. In most cases, this knowledge was acquired already after having been diagnosed with HIV and TB and having received services and treatment. The sources of this comprehensive knowledge of HIV and TB were doctors, outreach workers, as well as PLTB and PLWH themselves who were exchanging their knowledge and experience on how to maintain their conditions, and health. While before, their knowledge and practices of using this knowledge were not quite adequate, which resulted in their infection with HIV and TB, – usually among family members, during collective drug usage, and in penitentiary institutions.

5. In 2012, the MARPs mentioned the improvement in the diversity and comprehensiveness of messages on HIV and TB at state health facilities, however, they also mentioned that information on HIV and TB had significantly reduced on TV, radio, mass media, in the streets and public transportation, etc., – in these places messages were usually brief and cursory, and implicative, and the MARPs would rather guess than understand what was said about TPs, VCT, STDs, HIV and TB.
6. Among the obstacles to acquiring proper knowledge the following were mentioned: young people who have been taught the Latin alphabet find it difficult to understand messages written in the Cyrillic alphabet, while adults who know only the Cyrillic alphabet can hardly read messages in Latin; the Russian-speaking population does not understand messages in the Uzbek language, and vice versa.
7. The informants' statements are as follows:
  - There is a trend of a significant increase and improvement of the awareness and experience (both positive and negative) of receiving services by PLWH and PLTB with their infection/getting sick and receiving services;
  - Among the PLWH and PLTB, there are many of those willing to share their knowledge and experience with MARPs and communities.
  - These PLWH and PLTB suggest to use their knowledge and experience for a trend opposite to the above mentioned, – namely, among the MARPs that are still in the situations of risk for HIV and TB, and, especially, among the MARPs of youth not yet covered by preventive knowledge and measures.
8. MARPs need to be provided with a key message that would clearly convey to them who has the right, and where and to whom they can turn to, with their questions, risks and problems. The main words in this message should be: *'voluntary, free, confidential and friendly services'*.
9. The knowledge the MARPs, PLWH and PLTB obtained was not only about HIV and TB but also about the peculiarities of the groups of population and the sites subject to the risks of HIV and TB infection. If in 2011 the informants were mentioning PWID and SWs, in 2012 they put special emphasis on returned convicts and teens not covered by NGO and TPs projects. In the same 2012, the MARPs and PLTB mentioned inexpensive catering facilities with cheap alcoholic beverages and snacks and poor sanitary conditions among the sites with a high TB risk.

### **MARPs, PLWH and PLTB experience of receiving services**

1. The informants stated that they had received good quality services not only when turning to these or those facilities but when employees of these facilities, volunteers and outreach workers were inviting them during personal visits or via the phone for VCT for HIV and TB, or were informing them about scheduled examinations during events with rewards in the form of food packages and reimbursement for public transportation, or when they were bringing medicines and preparations to those who were not able to visit health facilities or were bringing PLWH and PLTB to health facilities if they were not able to go there themselves.
2. Another proof of the improved quality of services provided to MARPs is that, unlike in the 2011 survey, in 2012 the informants did not mention any cases of suicide among PLWH and PLTB after being informed on their HIV or TB status or in case of aggravation of their condition, which, in its turn, is an indication of the improved quality of VCT and, especially, of the psychological support on the part of the AIDS Center and ACR employees, and of the fact that these facilities followed the principles of voluntary diagnostics and friendly consultation. Nevertheless, the informants emphasized the fact that, because some medicines and services had to be paid for, some PLWH and



PLTB would not start, or stop receiving treatment to save money and maintain the living standards of their family members.

3. Among those who find it hard to get VCT and health services are ‘newcomers’ – those who have come to Tashkent from provinces (including SWs). These MARPs do not have local registration, hence they either cannot apply to a health facility or do not know that they can receive anonymous services at AIDS Centers and TPs. According to the SWs, some of these newcomers are using services of ‘cheap’ SWs without PPDs and without consequent STD and HIV testing. The informants mentioned the reduction in the activities of outreach workers, AIDS Centers and TPs in the provinces and rural settlements. Their statements are based on communication with these ‘newcomers’.

4. The reason why the PLTB distrust VCT is errors in tests and diagnostics, which the PLTB believe is the result of doctors’ incompetence, and of poor quality of equipment and X-Ray films. The PLTB mentioned cases when they were diagnosed, for example, with TB after a prolonged examination and treatment of HIV and TB symptoms that doctors thought were the symptoms of a cold; or, vice versa, – when doctors diagnosed TB which would later be proved to be a wrong diagnosis.

5. PLWH and PLTB state that, overall, they do not feel discriminated and stigmatized by doctors, besides in some cases at the KVD, at their local polyclinics by mid-level staff and district doctors, by self-governing bodies personnel, neighbors, and, – which is especially painful for them, – by family members and relatives. Nevertheless, the PLTB and PLWH mention the reduction of cases of stigmatization and discrimination.

6. PLTB and PLWH can see the increasing friendliness and timeliness of doctors’ and nurses’ services not only at TPs, their attentiveness and control over the adherence to treatment course, procedures and drug regimen at AIDS centers, at the TBPC, and at prison health facilities. Some of the informants mentioned better conditions at health facilities after renovation of premises and installation of new medical equipment, – like, for example, at the TBPC.

7. As for gaps in services, the informants mentioned the increasing segregation in the quality of services and the accessibility of efficient medical preparations at the TBPC and at the ND depending on patients’ paying capacity, as well as the lack of friendliness and cases of violation of PLWH and PLTB confidentiality status by family polyclinics mid-level and nursing staff. At the same time, the informants mentioned that such cases were being thoroughly investigated, and offenders usually dismissed.

*PLWH+TB-F-39 “This happened two years ago. One woman who lived in our apartment building had worked in Italy as a prostitute, where she got infected with HIV. Her child was HIV infected, too. A nurse came one day and informed her neighbors about her condition. This woman was in hysteria. We complained about that to Jakhangir (an outreach worker). He found out whom that nurse was. But she quitted immediately to escape the responsibility. There was another case when a polyclinic nurse told U.’s mother that her son’s friends are HIV infected. However, U. himself was infected, but his mother didn’t know that. That nurse was fired, too”.*

### **PLWH and PLTB needs**

In this section and further, we will discuss MARPs’ special needs, which can be used by specialists when developing recommendations for certain actions within current or future projects.

1. Participants of all groups mentioned that Dialogue Project should devote special attention to teens and young people of the new generation of PWID and SWs, in accordance with their needs in knowledge and the necessity to overcome the distrust on the quality of VCT services.

2. PLTB and PLWH, on the whole, are receiving accessible and good quality services when seeking assistance, being examined or hospitalized. Nevertheless, some PLTB and PLWH from low-income families face obstacles to accessibility and quality of treatment in the hospitals, where they are not being provided all necessary medical services and are being offered poor nutrition or inadequate conditions (the state of premises, etc.) These PLWH and PLTB do not have enough money to pay for additional food, for additional services and medicines for ART. For example, the total amount of average expenses for treatment for PLTB has increased since 2011 from 600 up to 800 USD (in the Soum equivalent) because of a drop in the accessibility of free medical services, and, especially, because of rising prices for medication, most of which PLWH and PLTB have to buy themselves, – especially, for treatment of associated illnesses.

3. PLWH and PLTB need stable income that would at least be enough for proper nutrition at home. A disability allowance (if you have it) is hardly enough to cover expenses for your own and your children's physiological needs (especially, if you are a single woman or if your husband and children have the PLWH and/or PLTB status).

4. The PLTB mention gaps in occupational safety as one of the reasons for TB infection.

*FGD-PLWH-M-TBt-45 "The main reasons for TB are cold temperatures, dampness and air pollution. I have had a job for 6 years where we could hardly see each other because of dust. We were only being provided with respiratory masks which would usually last for no more than five minutes."*

5. The informants are facing an increase in their needs during certain seasons when they require special attention and services.

*PLWH+TB-M-41 "Our condition would aggravate in the spring and fall, when we would lose weight, have nausea and weakness, lack appetite."*

6. Able-bodied PLWH and PLTB (those without a right for disability allowance or not eligible for such an allowance due to different reasons), need employment, – especially, stable employment – not only from the point of view of income, but from the point of view of socialization as well. Unemployment is being perceived as exclusion from communities, causes stigmatization and discrimination, which results in depression. Some of the PLWH and PLTB suggest creation of something like Rehab Centers where they could live and work. These settlements could offer kind of municipal housing where they could move to avoid infecting their family members and relatives, or escape their stigma and discrimination. They started suggesting this after the authorities started to provide assistance to them, like in the following cases:

*FGD-PLWH-F-TBt-33 "They are now renting rooms in special hostels for PLWH. Some of my friends got such a room. For that, you have to come to your khokimiyat and collect necessary papers."*

*FGD-PLWH-M-TBt-45 "I've got a friend who just came back from a prison. He's got tuberculosis. He was given a room in a hostel. They gave it to him because he's an orphan."*

*FGD-PLWH-M-TBt-45 "When they are releasing those who've got TB they would either start receiving an allowance, or would get immediate hospitalization."*

7. The informants are mentioning cases of creation of rehabilitation centers by religious organizations, and they believe that this mostly meets their needs.

*PLWH+TB-M-41 "We have a Rehab Center, and rehabilitation lasts 9 months. It's for free and confidential. We are giving this Center's phone number to everybody. It's a Center for rehabilitation from drug and alcohol addiction. The Church has been providing assistance to us since 2006. It has its own program, and a regime that has to be observed. It's all for free. They would start working there themselves, to keep themselves, to pay for meals and housing. They are working for themselves. For example, refurbishing apartments. So far, we have 5 people, but if we have 100 we will rent 2-3 houses for them to live in. There is a similar Rehab Center in Samarkand."*

8. PLWH and PLTB suggest to expand the network and activities of their clubs/communities/associations (including virtual clubs on the Internet) established by some MARPs in the past with the assistance of NGOs, – they are communicating with each other there, sharing their experience and knowledge. Programs of assistance to MARPs could use these real and virtual networks to help them receive services which are in demand or which MARPs need but might be unaware of, including VCT services, as well as to help them build their knowledge and skills of maintaining their own health and protecting people around from risks of being infected.

9. MARPs and PLWH need a wider range and better quality of services provided by outreach workers, since they often do not have enough money to make a trip to receive VCT, or to get free syringes, condoms and medications. The lack of outreach workers (especially, females) is being explained by the informants by the lack of interest in such work, suggesting to increase incentives, especially, for female outreach workers.

*FGD-PLWH-M-HIVt-45 "They do not have a good incentive, otherwise they could do a lot more. If their salary depended on the results of their work then they would be interested in doing a better job. As far as I know they are being paid low salaries."*

*PLWH+TB-F-40 "I wish there were more women among them."*

*PLWH+TB-M-41 "I remember that in 2006 there were a lot of handouts, they would give you a jar of condensed milk, a package of coffee and tea. Outreach workers were on staff there and were being paid good salaries. Now they are being paid 200,000. That's all they are doing, they don't have any other job, - how can you survive on 200,000?!"*

10. PLWH and PLTB who are not quite physically capable of visiting the TBPC or their polyclinics, need to be provided with DOTS medicines and other necessary high quality medications.

11. MARPs, especially PLWH and PLTB, are quite disappointed with cancellation of the activities of a number of NGOs where they could receive some knowledge they needed, communication, psychological and financial support.

*"Out of all the NGOs, I think, only the Global Fund, Project HOPE and 'Intilish' are still functioning. Without their support to the AIDS Center and TPs, almost half of the MARPs, PLWH and PLTB would have been excluded from the assistance programs, and would have become sources of epidemics". Interview with an outreach worker, 2012.*

12. Some PLWH and PLTB still need to overcome stigma and discrimination, especially, in their families, therefore willing to participate in actions aimed at attracting attention to their needs by participating in meetings with the population, students, and health personnel, in TV and radio talk shows.

13. The gender peculiarity in case of a need in hospitalization is a lack of conditions to take care of children. Men in this case would go to a hospital without suffering a guilt complex, while women would often refuse to do that because of children who need their attention.

## **METHODOLOGY**

**The survey methods** are based on the qualitative methods of data collection and analysis, namely focus-group discussions with PWID, SWs, PLWH, PLTB, as well as in-depth interviews with PLWH diagnosed with TB.

**Location** – the city of Tashkent.

**Control and monitoring** over the survey was performed directly by representatives of Dialogue Project, the Republican AIDS Center and the Republican DOTS Center.

**Preparation of the survey.** Representatives of Dialogue Project and the Republican AIDS Center conducted training for representatives of '*Expert-fikri*' Research Center to teach its personnel the specifics of communicating with MARPs.

### **The sample and volumes of works**

In total, there were conducted 12 FGDs, of them:

- 2 FGDs with PWID, 2 FGDs with SWs, and 2 FGDs with PLWH on the topic of TB;
- 2 FGDs with PWID, 2 FGDs with SWs, and 2 FGDs with PLWH on the topic of HIV.

10 IDIs were conducted with PLWH who were also diagnosed with TB.

### **Recruiting MARPs representatives**

FGD participants were being recruited via outreach workers of Dialogue Project.

The size of each group varied between 7 and 10 people, averaging 8.

There were no representatives of high-income groups of population among the FGD and IDI participants, as well as persons under 20 years old due to their refusal to participate in the survey.

### **FGD method**

The FGDs lasted from 1 to 2 hours, and were conducted by an experienced moderator who had previously participated in more than 20 FGDs with MARPs. He was assisted by 2 persons: one was making notes, and the second one was in charge of equipment for recording phonograms. These phonograms were transcribed word by word, with notes on participants' non-verbal reactions.

Questionnaires and guidelines in the Russian and Uzbek languages to be used during the FGDs and IDIs were developed and tested with the interviewers of the '*Expert-fikri*' Center who had an experience of work with MARPs in previous similar surveys.

### **In-depth interviews**

TB patients out of PLWH were recruited via AIDS Centers and the TBPC using the same selection procedure as for FGD participants. In total, there were conducted 10 one-hour IDIs with PLWH diagnosed with TB at the moment of interview.

### **Data collection procedure**

Focus-group discussions were conducted in a specially equipped sunny and ventilated room with one-side mirror at '*Expert-fikri*' Center, where participants were guaranteed complete confidentiality

and comfort. All the participants could see and hear the moderator and each other since they were sitting at an ellipsoid table.

Questionnaires and guides for moderators contained questions and instructions for probing topics and answers.

In-depth interviews were conducted in places convenient for respondents, and some were conducted at 'Expert-fikri' Center in the same specially equipped room.

### **Data analysis**

The obtained informants' opinions and statements were presented in transcripts, and later in the analytical report, in accordance with the survey goals and questions.

The content of the present Report has been based on the informants' opinions and statements, and might not reflect the reality, or reflect it in a distorted way. Nevertheless, in case the informants' statements disagree with the reality, there should be stipulated measures both to correct the actual situation with services provided to MARPs and to correct these perceptions and opinions.

Since the survey method was not based on quantitative methods - all of the informants' opinions should have equal rights and chances to be included into the analysis of statements.

Quotations from transcripts are to illustrate the conclusions of the Report, and are being accompanied by notes showing types of groups, the participants' gender and age (see *Glossary*).

### **Survey ethics**

All the informants were given a written document informing them about their right to refuse to participate in the survey or to quit it at any moment and at any stage of the survey. Each informant was to sign a consent letter confirming his/her voluntary participation in the survey and the obligation not to disclose the content of discussions or interviews.

All the informants were given written guarantees of confidentiality during data collection, analysis and storage.

The participants of the survey were informed about the use of recording machines during FGDs and in-depth interviews, as well as about persons sitting in the next room behind the one-sided window. Since the outreach workers would like their names to be mentioned in the survey, we listed their names in *Acknowledgments* Section.

## **PWID KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES**

PWID composite profile:

- Age: 20-47;
- Gender: men and women, both married and single;
- Occupation in different spheres: from the service to construction sector, or unemployed;
- Low-income families.

### **Knowledge and Attitudes towards TB**

**PWID knowledge of tuberculosis.** Both in 2011 and in 2012, t PWID, in general, showed good knowledge of TB, and not only mentioned tuberculosis of the lungs but of other organs as well. PWID are still aware of such symptoms of TB as symptoms similar to those of a cold, cough,

persistent fever, weight loss, weakness, excessive sweating, which some of PWID had tried to self-treat. PWID mentioned that these symptoms were seasonal, aggravating in the spring and fall.

**Sources of knowledge on TB.** In 2012, PWID knowledge and attitudes have significantly changed becoming deeper and more comprehensive, with the improved knowledge and experience of timely information and diagnostics that have become more accessible.

In 2011, the first important sources of knowledge for the PWID were communication with those already ill with TB or having been ill with TB and with health personnel of facilities where they received treatment for TB, printed materials, newsletters and TV.

*“I stayed at a hospital for three months, and was mostly associating with TB patients, and learned and saw quite a lot during these three months.” PWID-M.*

*“There was a TV program about hepatitis and tuberculosis.” PWID-22.*

While in 2012, the first important sources of knowledge were outreach workers, ACR employees (who were working with PWID only), however, posters at polyclinics were less frequently mentioned, and TV, radio and press were not mentioned at all.

*FGD-PWID-M-TBt-44 “I’ve been visiting Julia (an outreach worker) at the ACR. 2 months ago she told us about tuberculosis and HIV. She persuaded us to have our blood tested, and lungs examined.”*

*FGD-PWID-M-TBt-28 “The guys at the ACR (outreach workers) are giving out brochures on HIV, AIDS and tuberculosis, with clear explanation of everything. If we are not sure about something they would explain it to us on some days. Information is being presented in an interesting form.”*

*FGD-PWID-M-TBt-35 “It’s not only the brochures, - knowledge is being disseminated among us all. Some were ill with it, some have been cured.”*

*FGD-PWID-M-TBt-44 “I’ve learned a lot at the ACR. We used to have only general ideas: smear-positive and smear-negative tuberculosis; we just learned that there is also a drug-resistant tuberculosis.”*

*FGD-PWID-F-HIVt-37 “Lena Devyatova is giving lectures in Gagarin Street. We would try to come there every Monday.”*

*FGD-PWID-F-HIVt-26 “Each day we are discussing different topics.”*

In 2011, the PWID suggested that messages on TB should not scare the population and MARPs, but rather provide prevention knowledge and the awareness of the possibility to cure TB.

*“They should warn rather than scare. If people get scared this will start a mass hysteria!” PWID-M-26.*

*“They should adapt the information materials to different ages and genders. They should inform that you should take a fluorography test once in six months, and be health-minded, eat well, and shouldn’t smoke.” PWID-M-26.*

*FGD-PWID-M-TBt-42 “More than half of the population believe that tuberculosis is incurable, and that once you get ill you are going to die.”*

In 2012, the PWID mentioned that they were not only provided with knowledge by outreach workers and TPs, but with psychological support as well, inspiring hopes for recovery.

*FGD-PWID-M-TBt-44 “There are psychologists at the ACR who are helping us, - they are reassuring us, telling us that if you are ill it doesn’t mean you’re dead meat. The same about HIV. They are informing us about different treatment programs.*

*FGD-PWID-M-TBt-50 "They wouldn't let us lose heart."*

**Knowledge on risk groups for TB.** In 2011, the PWID described those having TB or at risk of catching TB as 'released prisoners', poor and undernourished persons, PWID in a depressed state and looking for a heroin dose to last one more day of life.

*"Everybody can catch TB, but the poor are most vulnerable. It can rarely happen to rich ones, and they can get proper treatment, while a poor person cannot afford it." PWID-M-26*

*"If one is only thinking about how to find heroin he would forget about his meals." PWID-M-32-HIV*

*"Those in a depressed psychological state. If I, for example, am not able to keep a family, if I don't have any income, if I am not able to do something, how can I enjoy my life?" PWID-F-36*

*"We know that there's little time left for us, and we are enjoying each day." PWID-M-36-HIV*

In 2012, the PWID were rather describing groups risk as PLWH, bums, alcoholics and PWID.

*FGD-PWID+PLWH-TBt-F-36 "I'm HIV infected, with a poor immunity, and I'm afraid of TB."*

*FGD-PWID-F-TBt-32 "Those who are undernourished; homeless who would sleep in apartment buildings basements or on the stairs."*

*FGD-PWID-F-TBt-40 "Alcoholics and drug addicts."*

**TB causes, modes of transmission and prevention methods.** In 2011, some of the PWID were saying that drug or alcohol abuse would trigger TB infection, since it results in a loss of appetite and poor immunity. Other PWID believed that drug use helps maintaining your health.

*"Drugs are saving us. If it were not for drugs we would have been dead long ago. Drugs improve our immunity." PWID-M-36-HIV*

In 2012, none of the PWID made such statements.

The PWID are naming the same modes of TB transmission: airborne transmission, sharing dishes with PLTB at home or inexpensive cafes.

*"One can catch the infection in public transportation. Mostly, airborne transmission." PWID-M.*

*"It's a bacteria. It can be transmitted anywhere. For example, with a plate or a spoon not properly washed at a canteen." PWID-M-26.*

*FGD-PWID-M-TBt-37 "Do you remember Petka? He never did time, however, two of his brothers did. They both had 'tubic' (TB), and still alive, but Petka who had not been in prison caught this diseases and died. One doesn't even have to be in prison to get TB."*

*FGD-PWID-M-TBt-35 "One can have 100 gram from a shared glass at a 'joint' and, if you have poor immunity, you could have TB as soon as within a month."*

*FGD-PWID-M-TBt-42 "There are still shacks in Yangiyul where everybody would drink from one and the same glass. (Yangiyul was mentioned not accidentally, since it is one of the centers of the ID market. Moderator)."*

In 2012, the participants for the first time mentioned TB risks as higher risks compared to HIV risks.

*FGD-PWID-M-TBt-41 "One can protect himself from HIV but not from tuberculosis. If you are jabbing (injecting IDs) in the right way you can be almost 100% sure you won't get HIV, but you can get TB anywhere."*

Both in 2011 and in 2012, there was an opinion that one of the ways of TB spread is intentional infection of other people, or failure to take preventive measures.

The PWID mentioned in 2011, and are still mentioning, the following TB prevention measures: ‘to eat garlic’, vaccination, high calorie diet and taking vitamins, regular medical exams, avoiding dust, cold temperatures and colds.

**Needs and possibilities for knowledge on TB.** In 2011, the PWID statement: ‘We would like to know everything about TB’ was a proof of their insufficient knowledge of TB.

*“How can you contract TB? How can you cure it?” PWID-M-22.*

*“I’ve got a kid, and I need to know how to protect him.” PWID-F-29-family*

*“Who will help me if I get sick if I’m an orphan?” PWID-M.*

*“Where could I get social aid with money or food?” PWID-M-32-HIV*

In 2012, the FGD participants did not ask questions.

Both in 2011 and in 2012, the PWID did not know the term DOTS, however, were aware of DOTS treatment duration and procedure.

*“You will be registered with the tuberculosis dispensary, they will call you up regularly reminding you to come for a sputum analysis and a fluorography test once in three months. Your principal physician will monitor the treatment progress.” PWID-M-37-married*

*A nurse explained how to take pills and proceed with my treatment.” PWID-F-29-married*

*“She gave me, for example, five packages of drugs, and told me to bring empty packages back to her later. After that I would be given more pills.” PWID-M-37-married*

*ГД-PWID-M-TBt-43 “As far as I know they would provide treatment to you for up to one year holding your job and salary.”*

*FGD-PWID-M-TBt-35 “First they are treating you for six months, and if after that there’s still a shadow they prolong treatment for the next six months.”*

Both in 2011 and in 2012, the PWID had a negative opinion about some TB medications.

*“Even under doctor’s control many wouldn’t take Tubazidum. Tubazidum makes you ‘go gaga’. Your body just cannot stand it”. PWID-M.*

*“My legs failed after Tubazidum, and joints were aching, and I was kind of giddily.” PWID-M-22.*

The PWID recommended to provide more comprehensive information about DOTS in information materials.

*FGD-PWID-M-TBt-43 “I would like to see a short clip on TV between promos: ‘Tuberculosis is curable if you come to the doctor in good time! The DOTS course will help you!’. They should inform not only those who are already ill but everybody.”*

### **Seeking Consultation, Treatment and Support**

The PWID, in case they get ill with TB, would first seek care from their family and close relatives, and then to their district doctors who are further referring them to doctors-specialists for consequent treatment.

Both in 2011 and in 2012, the PWID believed that seeking treatment is useful, however, only if this treatment is being accompanied with highly qualified specialists’ consultation, is timely and continuous.



*“One PWID couldn’t be diagnosed with tuberculosis for 5 months, - he had the mildest surface tuberculosis. He stayed in a hospital for five months, and doctors couldn’t figure out what the problem was. When he was already about to die they made a tomography and only then found TB.” PWID-M*

*“One should immediately visit a physician. However, some would advise: ‘Just stay at home, boy, and take raspberry jam’, and as a result your TB gets aggravated.” PWID-22*

*“My friend had TB. She was taken to the hospital in Sofia street. She stayed there for 8 months. In the beginning, she weighed 38 kg, with her height of 1 m 90 cm; now she’s 92 kg. She adheres to the treatment regime, and don’t drink. The treatment has helped.” PWID-M-38*

In 2011, some of the PWID believed that treatment is not always helpful, that is why some PLTB would get depressed and commit suicide. In 2012, the PWID did not mention any cases of suicide because of TB.

Both in 2011 and in 2012, the PWID accepted that diagnostics, consultation and treatment is accessible at polyclinic and up to PTPC. However, in 2011, the PWID were complaining about high prices and timeliness of services, especially for diagnostics procedures.

*FGD-PWID-M-TBt-43 “If you would come to your family polyclinic doctor and they would find out that you haven’t done fluorography in the last year they would certainly administer this test for you.”*

*“Our fluorography room is either closed, or they’ve run out of films, but if you pay them 7,000 Soums they would open immediately.” PWID-F-36 and PWID-M-36-HIV*

In 2011, the PWID mentioned cases when PLTB were being diagnosed or treated covertly at private clinics, by their acquaintance doctors. In 2012, there were no such statements.

*“There’s no difference if you come to a private clinic or to a public facility, - you’ll have to pay, anyway. However, in a private clinic they would at least do your tests properly. And they would not look down their noses at you.” PWID-M-36-HIV*

What was different in the PWID’ statements in 2012 was that they believed that services at health facilities became more accessible when assisted by outreach workers and TPs.

*FGD-PWID-F-TBt-39 “If you compare, for example, the TPs’ activities with what doctors, polyclinics and hospitals are doing, it’s like night and day!”*

*FGD-PWID-F-TBt-23 “If we decide to do HIV or TB tests I would call my acquaintance outreach workers and tell them that we’ve organized folks here. And you must know how difficult it is to gather those like us.”*

*FGD-PWID-F-TBt-45 “We are gathering because outreach workers would come and take us for our tests, and we don’t need to go anywhere and wait in lines, and then they would bring us home and pay for transportation.”*

*FGD-PWID-F-HIVt-37 “‘Hopovskiye’ (Project HOPE outreach workers) helped one of my friends to get outpatient treatment. She was diagnosed with both HIV and TB. She was not given any medicines at the tuberculosis dispensary. Outreach workers went to the TBPC and started to bring her free medicines once a week. Before, she had to buy medicines herself for a whole year.”*

*FGD-PWID-F-HIVt-35 “Besides, they are bringing food packages to her once a month.”*

*FGD-PWID-F-TBt-39 “I was sick, and was coughing for 2 months. I was coughing with brown sputum, and had persistent fever. I wanted to do fluorography but they told me at my*

*polyclinic: 'You've already done fluorography, come in 3 months, we don't have films now'. I went to the ACR and they diagnosed me with an acute bronchitis."*

## **PWID Needs**

The PWID are aware of, and continue to mention the following obstacles in treatment of TB and in consequent rehabilitation:

- Not everybody has an adequate perception of a chance to be cured from TB. The PWID have different opinions towards recovery from TB, ranging from 'it's curable' up to 'it's incurable', and these opinions have not significantly changed since 2011.

*"Sometimes it takes years, but sometimes one can cure this disease within three months."*  
PWID-M

*"Many people are dying of tuberculosis."* PWID-M-37

- In 2011, the PWID mentioned that services provided by health facilities are not quite quality services – starting from diagnostics and treatment up to the risks of breach of confidentiality. Nevertheless, in 2012, the PWID mentioned improvement of conditions at the TBPC:

### **2011 Quotations:**

*"I was taking a whole course of treatment for TB for several months, had consumed tons of drugs, and did all the injections. But then I had my tests done, and was told: "Sorry, but it appears that you didn't have anything!"* PWID-F-29

*"I came to see my physician. She knocked me on the back and asked: 'What do you feel?', then measured my blood pressure, and administered antibiotics 'out of a hat' (without any reason), - maybe because it was a young girl."* PWID-M-27

### **2012 Quotations:**

*FGD-PWID-M-TBt-37 "I'm coming to the tuberculosis dispensary for an exam, but they are telling me that they don't have X-ray films or that their machine has broken. I was referred to another polyclinic. But there an elderly doctor told me that I had never had any tuberculosis."*

*FGD-PWID-M-TBt-37 "I don't trust family polyclinics. They informed my co-workers immediately who started to treat me differently because of TB, although all I had was a bronchitis."*

*FGD-PWID-M-TBt-44 "They do not provide good treatment at the Republican TBPC in Sofia street, however, treatment at the tuberculosis Institute is acceptable."*

*FGD-PWID-M-TBt-28 "It's quite good now in Sofia, too, - they've built 2 new buildings. Nicely renovated. Very clean. New equipment. Plastic windows. However, there are 2 other buildings where it's not as good – everything is old, wooden windows."*

- Lack of pharmaceuticals, especially for treatment of illnesses and conditions associated with HIV and TB, resulting in need to purchase those, and lack of money for that.

- *FGD-PWID-M-TBt-43 "Treatment of tuberculosis should be free, - it's a governmental Program. However, it's another question how this program is being implemented."*

- *FGD-PWID-F-TBt-23 "You have to buy Streptomycin and Novocain yourself. They would only give you pills."*

*FGD-PWID-F-TBt-23 "Even in this DOTS program it happens sometimes that they don't have something, and we have to buy it with our own money. For example, to save the liver we are buying Apcosule. They are treating tuberculosis but ruining the liver."*

- No services provided to patients who have complications and find it hard to come to a health facility or polyclinic to get pharmaceuticals for HIV or TB.

*FGD-PWID-F-TBt-23 “Not everyone is able to come to get these pills. I cannot go to my polyclinic, I don’t quite feel well for that. You have to get up early in the morning before it gets too hot. I’m glad they’ve provided me with medicines for a whole week. Why couldn’t they bring them to us at home?”*

- Not enough income and falling living standards due to the lack of jobs or disability caused by HIV or TB, as well as lack of social support at the place of residence.

*FGD-PWID-M-TBt-42 “My neighbor turned to our mahalla. Her husband was temporary out of work, and they had to feed 4 kids. All they told her was: ‘You should sell your carpet while your husband is without a job, and feed your kids.’”*

- Lack of patients confidentiality or confidentiality of diagnosis, – not only because of health personnel but also because of the rules requiring that the information about TB patients is to be submitted to the place of residence and to SES that has to do disinfection, or when the procedure of social allowances distribution involves strangers who do not understand consequences of discrimination and stigmatization of TB patients after spreading information about them.

*“One of our employees was diagnosed with TB, and after that they made all the mahalla employees go check for TB.” PWID-M-32-HIV*

- Lack of knowledge in communities of the importance of providing social support to patients, and the necessity of information campaigns to be carried on in communities;

*FGD-PWID-M-TBt-43 “They don’t understand in our mahalla what tuberculosis is and how dangerous it is. How is the mahalla going to help if they themselves don’t know what TB is?! That it’s a threat to your neighbors as well! It’s better to help in the beginning than to end up with an epidemics. Some seminars should be organized for them. They should be taken to a family polyclinic and show them how many TB patients there are in their mahalla, and how many of them they refused to help.”*

*FGD-PWID-M-TBt-41 “They should be told to pay attention to TB patients in their mahalla, to come and visit them and to see how they are struggling to make both ends meet.”*

- Both in 2011 and in 2012, the PWID believed that there should be developed special public programs aimed at supporting TB patients during their treatment and rehabilitation, that social support should be provided in the form of food packages, and the knowledge about a healthy lifestyle should be promoted during the information campaigns.

*“I would say this will affect the wellbeing of not only one person but of the whole nation.” PWID-M-26*

*FGD-PWID-M-TBt-35 “They should be on a high-calorie diet.”*

*FGD-PWID-M-TBt-41 “The most important thing for TB patients is good nutrition. A slightest cold could trigger relapse of the disease.”*

*FGD-PWID-M-TBt-43 “Yes, if you take care of your health you could leave as long as 100 years.”*

*FGD-PWID-M-TBt-37 “You shouldn’t drink or smoke.”*

- Lack of rehabilitation centers for those without housing and income, and who, willing or not, is a source of the open TB infection. The PWID suggest improvement of conditions at health facilities that provide temporary housing for homeless or for those without papers detained by police.

*FGD-PWID-F-TBt-23 “They need to build a rehab center, only not the kind of a rehab center that they opened in Panelny. If you come there you would die even sooner. They’ve got everything there - scabies, bedbugs, TB patients, syphs, you name it! No cups to drink from. If somebody brings a flask with water, everybody would drink from this flask. And nobody knows where it came from.”*

*FGD-PWID-F-TBt-32 “They are brining all those without passports there, those they would pick up in the streets. Then they let them go. They all sleep on the floor there.*

## **PWID Knowledge, Attitudes and Behavioral Practices towards HIV/AIDS**

**PWID Knowledge of HIV/AIDS.** In 2011, the PWID regarded that there were certainly not enough knowledge and channels of knowledge on HIV, especially for teenagers.

*“There’s very little such information.” PWID-M-32, PWID-F-28 and PWID-F-29*

*“My daughter is 15 years old. She’s made a tattoo on her body. I asked her if she had known that she could contract HIV, and she said that she hadn’t.” PWID-M-39*

In 2012, the PWID stated that their knowledge on TB had significantly improved in the previous year.

*FGD-PWID-F-HIVt-37 “Our knowledge has improved by somewhat 70%.” (Other FGD participants agreed with her. Moderator)*

In 2011, all the PWID had heard about HIV, however, under the name of AIDS, and had a phobia of AIDS. Besides, they believed that HIV is dangerous because there is no guaranteed protection against it, and no cure of it.

*“HIV and AIDS is one and the same thing.” PWID-M-31*

*“HIV will always end up in AIDS.” PWID-F-39*

*“AIDS is a horrible disease, it’s fatal.” PWID-F-31 and PWID-M-41*

In 2012, the PWID began saying that HIV and AIDS was not one and the same thing, and that HIV not necessarily results in AIDS, and if a person is taking medicines and risk free behavior he can live a long life.

*FGD-PWID-F-HIVt-35 “If before they would always talk about AIDS, now they are talking about HIV.”*

*FGD-PWID-F-HIVt-26 “My friends would say that AIDS means you are certainly going to die, but if you’ve got HIV you will live if you take care of your health and bolster your immunity.”*

*FGD-PWID-F-HIVt-34 “If you take precautions, and take pills all the time, do not drink vodka and do not take drugs.”*

*FGD-PWID-F-HIVt-20 “One can live long with HIV. Most important is not to miss your treatment.”*

*FGD-PWID-M-TBt-28 “Only those are dying who ‘hit the bottle’ and know that they’ve got tuberculosis. They would drink ‘to the bitter end’, and wouldn’t go for any treatment.”*

Both in 2011 and in 2012, some of the PWID believed that you could tell if a person is HIV infected by his/her appearance, other mentioned that only a blood test could show if a person has HIV.

*“An HIV infected person is losing weight and looks sick.” PWID-F-31*

*Only a blood test can prove if you have an infection, however, there are a lot of errors. One girl committed a suicide because of such an error.” PWID-M-31*

In 2012, unlike in 2011, some of the PWID mentioned the ‘window period’ and the necessity of regular VCT.

*FGD-PWID-F-HIVt-33 “If you’ve got HIV, a blood test might not show it from three up to six months.”*

*FGD-PWID-F-HIVt-35 “The first blood test might not show HIV. One should do several blood tests.”*

**Sources of information on HIV/AIDS.** In 2011, the PWID mentioned the following sources of knowledge on HIV they had access to (from the most informative to the less informative):

*“Mostly communication and TV screen.” PWID-M-34*

*“Neighbors and friends, or I even read booklets at a hairdresser’s once.” PWID-F-35 and PWID-F-28*

*“I’ve got some acquaintances who are HIV-infected, I communicate with them. They’ve had it for several years already.” PWID-M-39*

*“They have such information at any polyclinic - on the walls, in booklets, etc.” PWID-M-31*

*“I heard it once on ‘Grand’ radio station.” PWID-M-34*

*“There were girls at the Gorky metro station who were giving away small brochures.” PWID-M-31*

*“I saw posters in the streets on December 1, - the Day of Combating AIDS.” PWID-F-29*

In 2012, the first on the list of such information sources were outreach workers, personal communication between PWID at TPs, etc. Attractiveness of outreach workers and ACR as sources of knowledge can be explained by such an incentives as free syringes, condoms, VCT and reimbursement for trips to TPs.

*FGD-PWID-M-HIVt-27 “For a year or more already we’ve been learning from the guys - Viktor and Alexander (outreach workers).*

*FGD-PWID-F-HIVt-30 “We received brochures from them, were reading and studying them.”*

*FGD-PWID-F-HIVt-35 “Outreach workers would always meet with us at least once, two or three times a month.”*

*FGD-PWID-F-HIVt-35 “I was visiting the Anonymous Room, and was learning information there from outreach workers.”*

*FGD-PWID-F-HIVt-30 “They are giving away syringes, condoms, arranging free trips to TPs.”*

*FGD-PWID-F-HIVt-35 “They have stands in all polyclinics saying: HIV is..., AIDS is...”*

*FGD-PWID-F-HIVt-37 “However, at polyclinics they wouldn’t tell you about HIV and AIDS when you are coming for a blood test.”*

*FGD-PWID-M-HIVt-27 “People themselves would learn about HIV on the Internet. Some organizations are holding special conferences and exhibitions. However, you can rarely hear anything about HIV and related issues on our TV. They would say little about this disease, or would say that we don’t have this problem.”*

The PWID would still avoid discussing HIV issues with friends, partners, close relatives who are not PWID, however, they would discuss HIV with those who are PWID, like them.

*“I am ashamed to talk about it with my relatives.” PWID-F-35*

*FGD-PWID-F-HIVt-30 “We have a certain place where, say, once a month we would gather - 5-6 of us. We would sit there, talking, discussing our problems. However, before coming there each of us would take a dose. Otherwise it’s no fun.”*

*FGD-PWID-F-HIVt-37 “We would rather communicate with each other than seeking for information in mass media.”*

**Knowledge on HIV and STD risk groups.** In 2011, some of the PWID believed that all the people are subject to the risk of HIV, especially, the poor and undernourished, with immunity not strong enough for HIV.

In 2012, the PWID did not mention the poor, and believed that to risk groups are those who use IDs without any precaution and those who have promiscuous sexual life; therefore the following groups are subject to the risks:

*FGD-PWID-M-HIVt-47 “If you are a drug addict, your living standards don’t matter.”*

*FGD-PWID-M-HIVt-47 “Single persons.”*

*FGD-PWID-M-HIVt-27 “Those who have promiscuous sexual relations.”*

If in 2011, foreigners and former prisoners were mentioned among the risk groups, in 2012 foreigners and prisoners were replaced with labor migrants coming back from other countries, or those moving within the country in search of jobs, especially, ignorant youth from provinces – ID users.

2011 Quotations:

*“I was in prison for eight years. They would bring many drug addicts-prostitutes with HIV.” PWID-F-29*

*“Newcomers do not know anything at all about STDs. But how would they know?!” PWID-M-39*

2012 Quotations:

*FGD-PWID-F-HIVt-30 “There are many prostitutes and workers in Tashkent coming from provinces. Many men wouldn’t use condoms when they are having sex. They would sleep with drunk prostitutes.”*

*FGD-PWID-M-HIVt-47 “It’s mostly youth that are at risk.”*

**Knowledge on the modes of HIV transmission and prevention.** All the PWID knew and know the modes of transmission of the HIV infection: sharing syringes when taking IDs, unprotected sex, and at health facilities – contact with tools that might have PLWH’s blood.

In 2011, some PWID mentioned that non-treated flu could transform into HIV, or that a person can catch the infection after a simple contact with an HIV infected person or his things. There were no such statements in 2012.

In 2011, the PWID-SWs stated that the main reason why the infection was spreading was the use of IDs, while in 2012 they believed that the infection is being spread by SWs.

In 2011, very few PWID mentioned from the mother to her baby mode of transmission. In 2012, this mode was more frequently mentioned.

*FGD-PWID-F-HIVt-33 “An HIV infected mother does not necessarily give birth to an infected child. However, HIV can be transmitted via blood and mother’s breast milk.”*

*FGD-PWID-F-HIVt-26 “I had a baby, and after I had read a brochure I decided not to breastfeed him due to the risk of infection.”*

In 2011, some PWID were sure that HIV infection does not necessarily being transmitted during sex.

*“If a woman carries the HIV infection it doesn’t mean that a man will contract HIV from her.”*  
PWID-F-28

*“One of my acquaintances met a girl and told her that he had HIV. They lived together for 3 years. They were not using condoms. Once in three or six months they would go to a doctor and have a checkup. He had positive HIV test results, however, her results would always be negative.”* PWID-M-27

In 2012, the PWID did not make such statements, and mentioned the following measures of HIV prevention:

*FGD-PWID-F-HIVt-30 “There are three ways of protection against HIV: not to share your syringe with anybody when using IDs, use condoms when having sex, not to breastfeed your child. This is what Julia and Jakhangir (our outreach workers) told us.”*

*FGD-PWID-F-HIVt-33 “You should always use your own syringes.”*

*FGD-PWID-F-HIVt-30 “One should only use his own razor and toothbrush. Never use shared cups for making IDs. However, you can share kitchen dishes with other people.”*

*FGD-PWID-F-HIVt-20 “HIV cannot be transmitted via saliva.”*

*FGD-PWID-F-HIVt-37 “You can even share towels.”*

In 2012, some PWID started to think that one could catch HIV in a pool if an HIV infected person with a bleeding cut had used it.

*FGD-PWID-F-HIVt-34 “My neighbor’s 16-year old son was swimming in a pool, and caught the infection there. Within one and a half months he turned into a skeleton.”*

*FGD-PWID-F-HIVt-30 “I think an HIV infected person with an open cut had swum in the pool, and the boy had an open wound, too.”*

**Suggestions on dissemination of the knowledge on HIV.** In 2011, some of the PWID suggested that MARPs and the population in general, should be frightened by consequences of HIV. There were no such suggestions in 2012.

Both in 2011 and in 2012, the PWID suggested that meetings with PLWH should be organized in communities, as well as talk shows on TV, since it is mostly specialists who are talking about HIV but not PLWH themselves. Such meetings will increase people’s interest and trust to the knowledge, and will allow minimizing stigmatization of PLWH.

In 2012, for the first time suggestions were made to disclose statistical data on HIV cases in the country.

*FGD-PWID-M-TBt-28 “Outreach workers are saying that 22,000 PLWH is official statistics, however, nobody knows how many of them are there in reality.”*

### **Practices of Seeking VCT and Related Services**

In 2011, some of the PWID had heard about consultation rooms and TPs, others unaware, or were not sure if those services are free, and did not know where they could seek consultation or get tested.

*“You would think: ‘Where can I go, with whom should I go, whom should I turn to, and how much it would cost me?’ PWID-F-29*

The former PWID stated that some TPs had been closed, the others were too far away from their place of residence, and did not have enough syringes for everybody.

*“I’ve heard that such centers and Anonymous Consulting Rooms are in each rayon. One of my friends would get syringes and condoms there. He advises me to go there for a blood test.” PWID-M-30*

*They would give you two syringes per day, and for that I have to make a trip from Chilanazar to Sergeliy or to Sputnik. The bus fare is too high these days.” PWID-M-32-disabled*

Both PWID in 2011 had doubts that their confidentiality in these TPs would not be violated.

*“I doubt that they will keep it confidential, that is why I’ve never visited them and do not know of such anonymous rooms.” PWID-F-31*

*“I don’t think good doctors would work at these Anonymous Consulting Rooms.” PWID-M-39*

In 2011, some PWID mentioned that HIV testing was usually being done under anonymous codes, however, this anonymity is being broken as soon as you have a positive result for HIV, – after that they would ask for your passport and inform the third parties; all this results in violation of confidentiality, which is an obstacle to seeking VCT.

*“I came once to an Anonymous Room at the Chilanazar metro station. They told me that it’s all confidential and that I could tell this to my friends and acquaintances. You can give them any name or any number instead, or they themselves will assign a code to you”. PWID-M-31*

*“One of my friend’s acquaintances had had a car accident, and she went to a blood center to donate blood. It turned out that she was HIV infected. Police came to her house to inform her about that. Her husband beat her up.” PWID-F-27*

*“One of my friends came to an Anonymous Room and had his blood tested for HIV. His results were positive. They told him to bring his passport so that they would make a note in this passport about his HIV status. After that he has been called up to different organizations.” PWID-M-39*

*“I donated blood at the N. polyclinic. A week later their personnel came and asked my neighbors if they knew where I was. They said that I had AIDS.” PWID-M-39*

In 2012, all the PWID knew about the TPs and their addresses, phone numbers, and all of them stated that VCT services, syringes, condoms, and alcohol wipes were accessible and free, and did not doubt confidentiality of these services.

*FGD-PWID-F-HIVt-all. “AIDS Centers and TPs, outreach workers are providing us with all the services we need, and even with those that we were not aware of before.”*

*FGD-PWID-F-HIVt-35 “These days, they have Anonymous Rooms at each family polyclinic.”*

*FGD-PWID-F-HIVt-37 “They are telling us about HIV there, and giving out brochures.”*

*FGD-PWID-M-HIVt-27 “Outreach workers were taking us to TPs for blood tests. We also had fluorography there. They also organized training seminars and meetings for us. I hadn’t turned to anybody before I met outreach workers.”*

*FGD-PWID-F-HIVt-37 “Even if you are not an PWID, you can come there to have your blood tested. We would call an outreach worker and ask him for a voucher to do a blood test.”*



*FGD-PWID-F-HIVt-37 "I was accompanied by an outreach worker who paid for my trip to the Friendly Services Room at the Drug Rehab Center. I wanted to know which tests I needed to get hospitalized."*

*FGD-PWID-M-TBt-50 "We received consultation with their help."*

*FGD-PWID-M-TBt-37 "At the AIDS Center, - mostly, near the New Year's eve."*

In 2011, the PWID mentioned violation of confidentiality of their HIV-status. In 2012, they already did not mention these risks but mentioned cases when polyclinic health personnel were being dismissed for violation of confidentiality.

*FGD-PWID-F-HIVt-30 "These were polyclinic nurses and doctors. As for workers of Anonymous Rooms, they do not disclose this information."*

*FGD-PWID-F-HIVt-35 "One can do an anonymous blood test for HIV at an Anonymous Consulting Room, and nobody except this Anonymous Room employees will know the results of this test."*

The PWID still believe that there are currently no better facilities than TPs for obtaining necessary information and receiving consultation. This is, probably, because the PWID regard outreach workers of these Anonymous Consulting Rooms as 'their allies', because they are like themselves.

*FGD-PWID-M-TBt-37 "It's all about trust in them (TPs and outreach workers)."*

*FGD-PWID-M-TBt-43 "Some of them came from our midst, that is why we trust them. There's a guarantee that they won't give us away."*

*FGD-PWID-F-HIVt-35 "If I am jabbing with somebody else I would tell them that if they need assistance they could come to the ACR who will always help."*

Some of the PWID, after having had some experience of receiving services from outreach workers, started to recommend TPs' services to their close relatives, some of whom followed their advice whereas the other still refuse seeking VCT.

*FGD-PWID-F-HIVt-33 "My husband went there, too, for a blood test. We went there together, and with Julia and Jakhangir (outreach workers)."*

*FGD-PWID-F-HIVt-20 "When I told my husband about it he asked: 'You don't trust me? Are you afraid?'. Not everybody would go there, because everybody is sure he doesn't have it."*

*FGD-PWID-F-HIVt-35 "I suggested my husband to do that, and he told me: 'Get out of here! Maybe you want me to bring you a medical certificate?!'."*

*FGD-PWID-F-HIVt-34 "I offered it to my husband, but he said: 'Let's just divorce, and you'll find someone else'."*

*FGD-PWID-F-HIVt-33 "They find it humiliating."*

## **Knowledge and Attitudes towards STDs**

Both in 2011 and in 2012, the PWID had quite a good knowledge about STDs, – they mentioned hepatitis C, syphilis, trichomoniasis, gonorrhea, chlamydiosis, etc. The symptoms of an STD they mentioned were discharge, itching, redness.

*"I think there are no such people who haven't heard about that." PWID-M-41*

*"You have friends who have caught 'this', and you are discussing these issues with them, sharing your positive and negative experience." PWID-M-31*

The sources of knowledge about STDs, both in 2011 and in 2012, were distributed in the following order, by getting elder:

*FGD-PWID-F-HIVt-20 "I learned about them at school. Later, we told about them at the college."*

*FGD-PWID-F-HIVt-35 "We all learned about it this way, - first at school, then at a college, then at work. Later you learn about it from friends and relatives."*

*FGD-PWID-F-HIVt-34 "I learned about it from my husband."*

In 2012, the following source was added to this list:

*FGD-PWID-F-HIVt-37 "I was told about them by an outreach worker."*

*FGD-PWID-F-HIVt-34 "We all learn about STDs from our outreach workers."*

**Knowledge about risk groups for STDs.** Both in 2011 and in 2012, the PWID mentioned the following risk groups for STDs due to the risks of ignoring PPDs, irrespective of well-being and age. In particular, the PWID emphasize cases of risks after having taken an ID dose or alcohol.

*FGD-PWID-F-HIVt-37 "Prostitutes."*

*FGD-PWID-F-HIVt-33 "Drug addicts."*

*FGD-PWID-F-HIVt-37 "Gays."*

*FGD-PWID-F-HIVt-30 "Boozers."*

*FGD-PWID-F-HIVt-30 "There is one woman, she's 40. She never has money for a booze. She would just come to a 'joint' and sit there until somebody gives her a cup of wine. Would she care about a condom after a cup of wine?!"*

The PWID believe that men are at a higher risk than women since women, – including SWs, – are more likely to use condoms not only to prevent STDs but pregnancy as well.

*"Men are careless about that. While a woman would try not only to prevent an STD but especially pregnancy." PWID-M-39*

**Knowledge and practices of using personal protection devices.** All the PWID know about such preventive measure as condom, and are getting information on them, – as stated by them, – 'everywhere': at school, on television, from their parents.

*"As far as I know, they are talking about them at school these days, too, not hiding anything." PWID-M-31*

The PWID mentioned condoms as a mandatory means of protection against STDs.

*FGD-PWID-M-HIVt-27 "I would always have it."*

*FGD-PWID-F-HIVt-35 and FGD-PWID-F-HIVt-37 "That is 101!"*

The PWID still believe that condoms are not always being used in the following cases.

*"If you are drunk." PWID-M-41*

*"If you trust your partner (though you are wrong) or want to have more pleasure." PWID-F-39*

*FGD-PWID-F-HIVt-37 “If I’ve taken a dose anything can happen, even without a condom.” (the FGD participants are laughing and agree that the same sometimes happens to them, too)*

*FGD-PWID-F-HIVt-37, FGD-PWID-F-HIVt-35, FGD-PWID-M-HIVt-47 “After you’ve had a ‘dose’ you will hardly think about that.” (about a PPD)*

Some PWID believe that after you have had an ID dose you already do not think about sex because drugs themselves are better than sex.

*“After drugs you are not interested (in sex).” PWID-M-41*

The PWID still believe that PPDs are not needed if you have a regular partner, if both partners are in good health and trust each other. However, with occasional partners, you would need PPDs.

*FGD-PWID-F-HIVt-35 “I know one man. He’s married. I know that he doesn’t sleep with anybody but me and his wife. I’ve been with him for a long time, and have had my blood tested. I’m 100% sure about him. That is why I’m not using condoms with him. However, with others, I use condoms all the time. You use condoms if it’s for money, but if it’s love you don’t need it.” (FGD participants laughing approvingly).*

In 2012, there were statements about more common use of PPDs by men and women due to the following reasons:

*FGD-PWID-F-HIVt-35 “Men are more often using PPDs.”*

*FGD-PWID-F-HIVt-26 “Because they are afraid (of contracting a disease).”*

*FGD-PWID-F-HIVt-37 “They are usually married.”*

*FGD-PWID-M-HIVt-27 “Prostitutes are usually using condoms. They are not only trying to avoid an STD but a possible pregnancy as well.”*

**Needs in knowledge on STD.** Both in 2011 and in 2012, the PWID believed that urban citizens have enough knowledge about STDs, however, those arriving from rural areas lack such knowledge and are not using PPDs. That is why they are contracting infections and not getting any treatment because to get treatment you either need domicile registration, or it is too expensive, or you need to come to your district polyclinic thus making it possible that your family members, neighbors and acquaintances might find out about your disease. Some migrants prefer self-treatment. That is why, the PWID believe that information about STDs should be disseminated not only through social advertising on TV and in the press but at places where labor migrants work as well.

*“Why don’t they broadcast ads on television, - at least two-minute ads.” PWID-M-34*

*“Darakchi paper publishes some stories with hints, but no real information.” PWID-F-31*

**Diagnostics and experience of having STDs.** The PWID state that STDs are being diagnosed only in case somebody would seek health services, however, representatives of risk groups seek health services not often enough.

*FGD-PWID-F-HIVt-37 “Women themselves would rarely go there. However, when they need to have a health exam they are checking everything there.”*

*FGD-PWID-F-HIVt-35 “They are examining all women of fertile age.”*

Some of the PWID explain the reason for not going for diagnostics by high cost of diagnostics and treatment of STDs, by risks of violation of confidentiality or by low quality of treatment.

*FGD-PWID-M-HIVt-47 “Do you know how expensive treatment is? Money is the problem.”*

*FGD-PWID-M-HIVt-47 “One wouldn’t be able to cure such diseases anywhere anonymously.”*

*FGD-PWID-M-HIVt-27 “I think you will contract even more ‘nasty things’ at the KVD.”*

*FGD-PWID-F-HIVt-37 “Last year, they would do a smear test at the KVD for free. This year, they wouldn’t do it for free anymore.”*

*FGD-PWID-M-HIVt-47 “You would need 300-400 thousand to get rid of gonorrhea.”*

The PWID started to say in 2012 that services for STD treatment are available or free at the TPs.

*FGD-PWID-F-HIVt-37 “I had gonorrhea four months ago. I turned to Julia (an outreach worker). She referred me to the ACR who gave me free medicines. I was doing injections myself.”*

### **Knowledge, Attitudes and Practices towards IDs**

Some of the PWID still strongly believe that the number of PWID has dropped in the last years due to a drop in supply in the ID market, death of some PWID and the increasing prices for heroin. Other PWID state that a new generation of teen PWID is emerging due to the accessibility of Codacet.

*FGD-PWID-M-HIVt-47 “There were more of them before than now.”*

*PLWH+TB-M-39 “Some are dying, being replaced by others, - by a lot of teens. I can see more and more of them in my midst.”*

*FGD-PWID-F-HIVt-35 “There are some addicts who have been ‘on the needle’ for 25-30 years, then they quit, but then would start again. But some are taking huge doses and are perishing, and dying. I knew many guys who died within five years.”*

*FGD-PWID-M-HIVt-27 “There’s a lot of pills these days, ‘chemicals’. However, if before one package cost 1.5 thousand now it’s 40 thousand Soums.”*

*FGD-PWID-M-HIVt-36 “Heroin, too, costs 40 thousand Soums.”*

*FGD-PWID-M-HIVt-47 “It’s now too costly to be on drugs.”*

In 2012, there appeared such a belief that there is a drop in consumption of IDs as impact of outreach workers on PWID.

*FGD-PWID-M-HIVt-27 “We’ve become wiser after communicating with these guys - outreach workers.”*

*FGD-PWID-M-HIVt-36 “We’ve started to value our lives.”*

### **Practices of sharing syringes**

In 2011, the PWID stated that sharing syringes, needles and solutions for injecting IDs was becoming less common, partially because PWID-PLWH are now warning other PWID about their HIV status. However, sharing syringes, needles, etc. is still happening due to the following reasons:

- Being afraid that while you are looking for a syringe somebody might take your dose of ID;  
*“While he is running around to get a syringe somebody might use his dose.” PWID-F-29*
- Heroin is expensive, and it is easier to share expenses and take it together;
- There appeared new chemical IDs (Codacet) in the drug market, and you need an experienced coach to show how to prepare it;

- PLWH are already infected, and believe that after HIV they couldn't care less about infections like hepatitis C, etc.

In 2012, the use of shared drug injection equipment continues to drop among experienced PWID; however, teen PWID still continue sharing them.

*FGD-PWID-F-HIVt-35 "A hard-core addict will never use someone else's syringe or needle. He will prepare everything in advance. While teens won't do that because they are always in a hurry."*

*FGD-PWID-F-HIVt-30 "When you would start taking drugs with a hard-core addict he might not tell you: 'Don't use my needle, I'm HIV infected'. He just wouldn't care."*

- IDs (codacet and heroin) have become very expensive (40,000 Soums per dose), and it is easier to share expenses and take them together;

*FGD-PWID-M-HIVt-all "Of course, they are taking IDs in groups. One person wouldn't be able to buy it."*

- It has become a rule that one should disclose its HIV status to a group taking IDs together, and he/she might be physically and morally punished for violation of this rule.

*FGD-PWID-M-HIVt-47 "These days, everybody has its own syringe. Nobody would allow sharing one needle or 'rig'."*

*FGD-PWID-M-HIVt-40 "Everybody knows everything about each other. That is why, a drug user will not be taking risks. If he doesn't have a new syringe he'll use his own syringe used the day before."*

The PWID state that by 2012 the size of groups taking IDs together has dropped, on average, from 5 to 2, due to the following reasons:

*FGD-PWID-F-HIVt-35 "If PWID have enough money, a group is smaller, if it's a little money, a group is bigger."*

*FGD-PWID-F-HIVt-30 "If I've got enough money I'd rather take it by myself, not in a group. However, it doesn't happen frequently."*

*FGD-PWID-F-HIVt-26 "If you have a husband you are taking drugs with him only."*

*FGD-PWID-F-HIVt-37 "Even if you have money you need somebody else who knows where to get a dose."*

Both in 2011 and in 2012, the PWID stated that they were sharing cups from which they were filling their syringes with prepared drugs.

## **Withdrawal from Drugs – Incentives and Practices**

Some of the PWID believe that it is not possible to withdraw from drugs.

*"To kill an ID addict's dependence, you have to kill the addict himself." PWID-M-30*

Other PWID believe that an PWID can overcome addiction if he really wants it.

*FGD-PWID-F-HIVt-all "It all depends on a person, on his or her will."*

*FGD-PWID-F-HIVt-37 "I know one man who underwent treatment, and hasn't been using drugs for 10 years already."*

The PWID suggest to share success stories of drug rehabilitation within their community to encourage their efforts to overcome their dependence.

As before, the PWID are very concerned of cases of forced diagnostics and treatment.

*FGD-PWID-F-HIVt-37 “If you have a test at your polyclinic, and they find out something they will come to your house and take you by force.”*

*FGD-PWID-F-HIVt-37 “If you come to your district polyclinic according to your domicile registration, they will have your first, second and last name, and will make you go to the KVD for force treatment.”*

In 2011, the PWID believed that treatment should be voluntary, – however, it happens rarely, – while forced and frequently used treatment can only help overcome dependence for a short time in those with the lack of will and those who are using IDs as an escape from depression and personal problems.

*“Relatives and neighbors would sign a report, and police will force you do tests, and will take you to the ND by force.” PWID-F-31*

*“Police would take you there (to the Narcodispenser) by force through court action.” PWID-M-40*

*“However, as soon as you leave the ND you will start it over, again. On the very first day.” PWID-F-31 and PWID-M-41*

*“As soon as you jack up you forget about all your problems.” PWID-F-35*

In 2011, the PWID said that rehabilitation from addiction was rather excruciating and humiliating than too expensive.

*“The Narcological dispensary is worse than a jail.” PWID-M-41*

*“If you are an addict or a prostitute you can be beaten up there.” PWID-F-39 and PWID-F-31*

In 2012, PWID stated that rehabilitation from addiction was not so much humiliating but rather too expensive, – could be compared to the cost of IDs. This is the reason why some of those lacking willpower or from rich families would opt for IDs rather than overcoming addiction, even at drug rehabilitation facilities.

*FGD-PWID-M-HIVt-27 “You have to pay, anyway, whatever you’re doing.”*

*FGD-PWID-M-HIVt-47 “They will treat you at the psychiatric hospital. There’s a special department there, but you have to pay for this treatment.”*

*FGD-PWID-M-HIVt-47 “Treatment at the Republican Drug Rehabilitation Center is expensive, but all they do is give you a pill from withdrawal symptoms, or, if you are already having withdrawals, they would just tie you up for two days.”*

*FGD-PWID-F-HIVt-26 “Their patients are all so... high-ranked. They are pretty rich.”*

Some PWID are trying to overcome their dependence by replacing IDs with alcohol.

*FGD-PWID-M-HIVt-27 “They would start drinking wine or vodka.”*

*FGD-PWID-M-HIVt-47 “However, I think that vodka is worse for your health than wine.”*

In 2012, the PWID mentioned that they had access to replacement therapy services, however, had quite different opinions about this therapy:

*“There was a Red Crescent Program for drug addicts and HIV infected two years ago in Chilanazar, 15<sup>th</sup> Block, at the Drug Rehab Center. They were giving them methadone.” PWID-M-40, and PWID-M-39 and PWID-M-40*

*“They were giving methadone, but this drug was too bad for their health.” PWID-F-35*

*“Without methadone it’s even worse. IDs are hard to find, or too expensive, and teens would shift to codacet from which PWID would die very soon.”*

## **PWID Needs and Recommendations**

1. As before, the PWID’ main need is the necessity to overcome withdrawal symptoms, and the PWID suggest to resume the replacement therapy program.

*FGD-PWID-F-HIVt-37 “If one has withdrawals he should be able to call the ambulance and get pills to relieve withdrawal symptoms.”*

*FGD-PWID-F-HIVt-30 “That is, like it was before.” (FGD participant refers to the previously discussed replacement therapy)*

*FGD-PWID-F-HIVt-26 “Yes, it was cool before.”*

2. In 2011, some of the PWID did not know that there were governmental and private facilities where they could try overcome their addiction, or they regarded them as hardly accessible.

*“If there were drug rehabilitation clinics, and if addicts knew about these places where they could get treatment, they would come there from all over Tashkent.” PWID-M-27*

*“In such a big city only 60 beds in the Narcological dispensary!?” IDs-M-41*

In 2012, all the PWID were aware of these facilities, however, their services were not accessible for them due to their high cost.

3. In spite of the successful activities of outreach workers, PWID need more of them, especially, women.

*FGD-PWID-M-HIVt-40 “We would like to see more outreach workers.”*

*FGD-PWID-M-HIVt-40 “Health personnel are mostly working at their institutions, while outreach workers are themselves coming to us.”*

*FGD-PWID-M-HIVt-27 “I believed that, when they themselves came to me, and took me to the KVD, and then I took my friend to them.”*

4. The PWID mentioned periods when syringes were not available, lack or low quality of condoms.

*FGD-PWID-F-HIVt-26 “They don’t have enough condoms. We have to buy them ourselves.”*

*FGD-PWID-F-HIVt-34 “They have good syringes.”*

*FGD-PWID-F-HIVt-35 “They would give you 9 of them.”*

*FGD-PWID-F-HIVt-37 “About two months ago they started giving only 7. They didn’t have supplies for half a year.”*

5. The PWID mentioned lower efficiency of methods of informing MARPs about the risks of STD and HIV, – for example, less viewing of video clips with or without doctors’ comments, in groups of PWID or individually.

*FGD-PWID-F-HIVt-35 “I saw a clip about ten years ago, - sometime in 2003 in Chirchik. Health workers came, they showed us a video and answered our questions. They wouldn’t show us such videos anymore.”*

*FGD-PWID-F-HIVt-26 “After you’ve seen such video you would start using your brains.”*

*FGD-PWID-F-HIVt-30 “They should disseminate CDs with clips, and we should give them to each other.”*

6. The PWID, as before, believe that TPs should be located outside public health facilities, to eliminate the risk of violation of confidentiality.

*FGD-PWID-F-HIVt-all. “If an ACR is located at a family polyclinic, you don’t want to go there. But if it’s in some other place one can go there without fearing anything.”*

7. The PWID, as before, need to solve the problem of stigmatization resulting from the society’s perception that if a person is an PWID he or she must be HIV infected.”

*FGD-PWID-F-HIVt-35 “If people find out that you are an PWID everybody will be pointing fingers at you: ‘Here comes an AIDS carrier!’”*

*FGD-PWID-F-HIVt-37 “They are going to despise you.”*

*FGD-PWID-F-HIVt-30 “They will humiliate you, and sling mud at you all the time.”*

8. The PWID with HIV need confidentiality compliance, reduction of stigma and discrimination if a breach of confidentiality happens in communities, families and at work places.

*FGD-PWID-F-HIVt-37 “My neighbor has AIDS. She’s got two kids. Her neighbor would tell everybody that she is an ‘AIDS carrier’. Her neighbors just stopped talking to her.”*

*FGD-PWID-F-HIVt-35 “Even relatives turn their back on PLWH, which is why they are losing their housing. It’s not always that they would kick them out but they themselves are leaving their homes.”*

*FGD-PWID-M-TBt-50 “I knew a guy who used to live with his sister’s family, - her husband and kids. He told them that he had HIV, and after that they hounded him out of his own apartment.”*

*FGD-PWID-M-HIVt-27 “Employers would fire him even if he has been a good worker for 5-10 years.”*

*FGD-PWID-M-HIVt-47 “They would only fire him on a different pretext.”*

## **SWs’ KNOWLEDGE, ATTITUDES AND BEHAVIORAL PRACTICES**

SWs-FGD participants’ composite profile:

- average age: 35;
- divorced, or husband imprisoned or an PWID;
- unemployed, or occasional low-paid work in the service sector;
- have underage children.

### **Knowledge, Attitudes and Practices towards TB**

**Knowledge about TB.** In 2012, the SWs, – unlike in the 2011 survey, – were much more sure to mention complete and correct TB symptoms, measures of protecting themselves and people around against TB, duration and methods of DOTS treatment (however, not always knowing what the abbreviation DOTS itself means).



**TB symptoms.** Both in 2011 and in 2012, the SWs were naming TB symptoms sporadically and not as a set of symptoms, – probably because knowledge on these symptoms should have been delivered to them as a complex of symptoms, – and by all means as symptoms similar to the symptoms of acute respiratory diseases. This is exactly how SWs perceive the first symptoms of TB, – as those of a cold, – therefore trying to cure themselves with the help of self-treatment.

*“People wouldn’t come for tests in due time.” FGD-SWs-TBt-31*

*FGD-SWs-TBt-30 “They would go to a drug store and start taking pills to dull the symptoms of the disease.”*

**Sources of knowledge on TB.** In 2011, the SWs believed that if only one wants he would always find access to the knowledge on TB, – either coming to a doctor for consultation, or from friends, co-workers, on the Internet, etc. In 2012, they stated that the accessibility of getting consultation at polyclinics had reduced, mentioning cases of violation of confidentiality and/or not availability of TB specialist whenever they visited their polyclinics. In 2012, the SWs mentioned, first of all, such sources of knowledge as outreach workers, AIDS Centers, TPs and TB specialist’s consultation via them.

In 2011, the SWs mentioned such sources of knowledge on TB as mass media, ‘Zdorovie’ program on Russian TV (however, not on the domestic TV channels), as well as communication with those who already have TB or have been ill with it, posters at polyclinics, as well as books, etc.

In 2012, the first place on this list was outreach workers, – not only as a source of knowledge but also as those who used to take them to doctors for diagnostics and consultation, including diagnostics done during actions via TPs and AIDS Centers along with distribution of brochures among MARPs. The fact which shows SWs’ growing need in comprehensive knowledge is that they would like to know the statistics of TB in Uzbekistan, however, stating that currently it is not available they tend to believe in rumors about the increasing number of PLTB, among SWs including.

*FGD-SWs-TBt-31 “In one hospital I heard doctors saying that Uzbekistan is on top of the list of the CIS countries in the number of TB patients. However, it’s an inside information.”*

**CWSs’ attitudes towards TB** in 2011 were mostly based on the fear of this fatal disease, on the one hand, and laugh as the defensive reaction against this fear, on the other.

In 2012, the SWs mentioned TB as a fatal disease only if a person refuses treatment or interrupts treatment for a long time, or continues to consume alcohol and/or IDs. They also stated that TB is curable if treated promptly in its early stage and without interruption, already not laughing or being sarcastic about TB.

*FGD-SWs-TBt-35 “If a family and relatives do not offer their support to PLTB they decide that it would be better to die than to try useless treatment.”*

The SWs still regard TB as a ‘shameful disease’, accompanied by a guilt complex towards family members making them feel uncomfortable living with PLTB and bear additional expenses for their treatment.

**Modes of TB transmission and places of possible contraction.** The SWs were comparing the risks of contracting TB and HIV, and stated that risks of contracting TB are much higher than risks of contracting HIV, since one can protect himself against HIV observing preventive measures such as avoiding contact with anybody’s blood or items that may have anybody’s blood on them. However, it is much harder to protect yourself against TB, since the TB infection is being spread mostly by air and via common usage items.

In 2011, the SWs mentioned such places subject to the risk of contracting TB as a family with PLTB, inadequate work conditions abroad and prisons.

For the first time in 2012 there were mentioned inexpensive catering facilities where clients are consuming alcohol, work places in Uzbekistan with high risks for TB due to the lack of necessary technical and sanitary safety measures like working with cement, paint, garbage removal, dust, etc.

**Knowledge on TB prevention methods.** In 2011, the SWs' knowledge of TB prevention methods was occasional and sporadic. In 2012, the SWs were able to mention a full list of methods of protection against TB, including measures taken at their families (sanitation, hygiene, individual use of items of common usage, special veils for sputum, etc.). In spite of knowledge of protection means, the SWs still believe that it is not possible to protect yourself against TB in prisons, as well as in cases when PLTB are infecting people around them not observing necessary prevention measures.

**Preferred forms of obtaining knowledge.** The PLTB believe it necessary to more actively disseminate, and even deliver to SWs, brochures and booklets with addresses and phone numbers for getting diagnostics and consultation services. The SWs suggest that these materials should be handed out by doctors when receiving patients at polyclinics, at work places, – especially at those where workers are subject to dampness, colds and breathing in harmful substances and dust, including 'spots' where SWs are gathering and looking for clients.

In 2012, the SWs mentioned that they were receiving such brochures at the AIDS Center and, moreover, these brochures contained their recommendations.

*FGD-SWs-TBt-38 "They were giving us brochures at the AIDS Center, and were asking us what color of brochures we would prefer, and how it would be better to tell about TB and HIV."*

*FGD-SWs-TBt-35 "I liked that they were asking us and not just telling us what they had written and how they designed them."*

### **SWs' experience in receiving services**

**Practices of turning to health facilities for diagnostics and consultation.** In 2011, this practice was described by the SWs, starting with coming to a family/district doctor at a polyclinic, then doctor refers for further diagnostics (X-Ray, sputum analysis, etc.), then, – in case of diagnosing TB, – SWs would receive TB specialist's consultation at a polyclinic, followed by reference to TBPC for treatment.

In 2012, the SWs mentioned the first stage as an invitation received from outreach workers who made them come for diagnostics for TB via TPs and AIDS Centers.

*FGD-SWs-TBt-31 "I was afraid of getting X-ray radiation, however, an outreach worker told me that I shouldn't be afraid because it's a mild procedure at the AIDS Center, - not like the procedure you are taking once in 2 years."*

*FGD-SWs-HIVt-25 "Not everybody has money for a fluorography test. But there are employees at the AIDS Center and TPs who can really help you."*

Besides, the SWs were mentioning, – though less frequently, – that employers require that their employees should be taking a diagnostic test for TB once a year, medical checkup at polyclinics and prisons.

**Practices of receiving treatment services and assistance in social networks.** Like in 2011, the SWs first of all are turning to their families and close relatives (telling them to take preventive measures, and are themselves trying to observe them), then they are asking for assistance in treatment and expenditures, then are following their doctors' administrations and referrals, including coming to the TBPC.

In 2011, the SWs believed that to treat TB, you'd rather go to an 'acquaintance' doctor who will not violate confidentiality, because some of the polyclinic personnel (usually nurses) are not able to comply with confidentiality requirements.

*FGD-SWs-TBt-30 "Nurses live in the same mahalla as their patients, and if somebody is diagnosed with TB the whole mahalla will immediately become informed about it."*

In 2012, the SWs mentioned the unfriendly attitude towards PLTB by some polyclinic nurses, which the SWs with TB perceived as stigma.

*FGD-SWs-TBt-32 "Polyclinic doctors treat PLTB decently. However, the rest treat them as leprotic."*

In 2011, the SWs were mentioning Mama Rosa's (pimp) influence on SWs' willingness to seek VCT services, including TB diagnostics.

In 2012, the SWs did not mention any influence of pimps on SWs, in general and in any form.

In 2011, the SWs regarded turning to a mahalla for social assistance as humiliating, resulting in a loss of confidentiality and stigmatization, refusal in such assistance or a level of assistance which does not justify the effort.

In 2012, the SWs mentioned higher accessibility of assistance in mahallas, and that members of PLTB' families were provided with financial assistance at mahallas for 6 months, and food packages at the TBPC. The SWs particularly emphasized assistance provided by outreach workers in getting free medicines at polyclinics and the TBPC (including food items and getting a bed for treatment at the TBPC).

*FGD-SWs-TBt-33 M: "Outreach workers are helping us to receive medicines."*

*FGD-SWs-TBt-31 "They are giving us referrals for getting necessary preparations."*

*FGD-SWs-TBt-32 "If you bring a paper to the mahalla about your tuberculosis status they are helping you. However, you need to collect a lot of papers."*

*FGD-SWs-TBt-31 "Those registered with the TBPC are receiving food items once in 3 months, - for example, macaroni, cottonseed oil."*

Like in 2011, in 2012 the SWs mentioned cases of stigma and discrimination in families, – both on the part of men and women, – which resulted in PLTB' depression and termination of treatment.

*FGD-SWs-TBt-29 "One man got ill with tuberculosis. After he had had treatment at a hospital his family members cast him off because of a newborn baby. His wife divorced him."*

### **Possibilities and obstacles to receiving services**

TB diagnostics, consultations, assistance and treatment are available and accessible at health facilities – from polyclinics up to dispensaries. Nevertheless, the SWs mentioned the following obstacles and fears:

- The need to terminate their work or studies for a long time in order to get treatment. For women – lack of possibilities to find someone to take care of their children;
- PLTB' unwillingness to refuse from consuming IDs or alcohol;

*FGD-SWs-TBt-35 "Before, I could get Methadone and receive DOTS course. Now I would wake up in the morning, having 'kumar' (withdrawals). All I need is to find a dose, and I wouldn't care less about DOTS. The same with alkies."*

- Distrust of free treatment, in general, and of the quality of free treatment for PLTB, in particular, – especially, of treatment of associated illnesses (2011), and in 2012 – distrust of the results of diagnostics after a number of errors having occurred in diagnostics;

*FGD-SWs-HIVt-32 “I came to my polyclinic where they found some shadows in my lungs on an X-ray. But then Valera (an outreach worker) told me that I could do a test at an Anonymous Consulting Room. A doctor examined me there and said: ‘You don’t have any problems, Miss.’ I felt like I was reborn after that. They have more accurate results of X-ray exams at the AIDS Center.”*

- Not enough income to buy quality food, lack of free medications at the TBPC;

*FGD-SWs-TBt-38 “My neighbor was ill with tuberculosis. Her relatives were sending her money from Russia. She would say: ‘If you do not pay them they don’t have anything for you in the hospitals.’”*

Stigmatization continues to be an obstacle to getting proper diagnostics. They mention the contents of posters describing TB as a repulsive disease and forming a negative image of TB patients as one of the causes of stigmatization. The SWs’ response to external stigmatization is self-stigmatization with consequence depression which further aggravates TB.

If in 2011 the SWs believed that the first obstacle to treatment for PLTB was the lack of, or inadequate, diagnostics, consultation and accessibility of treatment, in 2012 it was insufficient social support of PLTB during treatment, rehabilitation and socialization in the form of helping them to find proper employment.

## **SWs’ Knowledge, Attitudes and Behavioral Practices towards HIV/AIDS**

**Knowledge on HIV/AIDS.** Some of the SWs in 2011 did not know what HIV meant, however, knew what AIDS was, which was perceived by them both as HIV and AIDS, and as one and the same incurable fulminant fatal disease.

*“Some changes take place in your blood, and patients do not live long.” SWs-30*

In 2012, the SCWs were already able to differentiate stages of HIV and AIDS, with their symptoms and prognosis. Some SWs did not hesitate to tell what the term ‘AIDS’ stands for (‘acquired immunodeficiency syndrome’). The SWs mentioned examples when PLWH are alive for 10 and 15 years, or even more (which was proven by the age of some PLWH who participated in our FGDs), knew all the modes of transmission and prevention of HIV, and after consultation and treatment started families and gave birth to healthy children.

*FGD-SWs-HIVt-25. “HIV is not the same as AIDS. One of my acquaintances has been living with HIV for 12 years already, looks quite healthy, eats well, but used to be an addict before. He found out about his diagnosis 2 years ago. His wife is HIV infected, too, but when she was pregnant she was consulted at the AIDS Center and treated. He gets proper treatment, got married, has three kids. His kids do not have HIV, however, his wife does.”*

*FGD-SWs-HIVt-27 “Yes, in the past the story was that AIDS is a plaque, death, the end of life. While now it’s on the contrary - you are being told that it’s not a death sentence.”*

The proof of improving knowledge and raising needs in knowledge is the fact that in 2012 some SWs accompanied their knowledge of the modes of HIV transmission by the knowledge about the risks of hepatitis C, and believed that this knowledge, as well as the knowledge of TORCH infections, should be disseminated among SWs the same way as the knowledge on HIV.

*FGD-SWs-HIVt-30 “Say, for example, TORCH-infection. I’ve heard about it but I don’t know what that is.”*

**Outward HIV symptoms.** In 2011, some of the SWs mentioned such symptoms of HIV as non-healing wounds on the body of PLWH, their desire to hide from the sun, persistent temperature of 37.5°, loss of weight, yellowish eyes, and weird color of their skin.

In 2012, the SWs were stating more frequently that it was not possible to distinguish an HIV infected person from a healthy one, therefore they believed that the only way of diagnosing HIV is a blood test for HIV.

In 2011, some of the SWs did not know that HIV could trigger TB as well as other diseases, and were learning about that from their own experience.

*“My brother has tuberculosis. We are visiting him in the hospital where a lot of young people are dying. He told me that many of them had HIV besides tuberculosis.” SWs-30*

In 2012, most of the SWs stated that HIV makes PLWH vulnerable to TB, having learned about that from outreach workers, at TPs and AIDS Centers.

**Knowledge on modes of HIV transmission, and prevention methods.** The SWs know that HIV is transmitted via sex, sharing syringes among PWID, via blood of HIV infected person or personal items with their blood on them, as well as from the mother to the fetus or the breastfed infant. However, all these modes were mentioned separately.

*“This infection is being transmitted via blood only. You cannot contract it if you shake hands with somebody.” SWs-34*

*“It can be transmitted both via breast milk and when a baby is still in the womb.” SWs-30*

In 2011 and in 2012, the SWs knew that the main method of protection against HIV during sex is a condom. In other cases, you shouldn’t use someone else’s syringes or equipment where there might be PLWH’s blood.

*“One can catch this infection at a dentist’s.” SWs-31*

*“I’m afraid now to go to a polyclinic gynecologist.” SWs-30*

*“Because they do not sterilize their equipment properly.” SWs-31*

In 2012, the SWs mentioned doctors and nurses were using syringes and tools trying to show they are doing their best to prevent HIV infection.

*FGD-SWs-HIVt-34 “Outreach workers suggested a one-time free consultation with a gynecologist. Although I did not feel well I clearly remember the doctor showing me how she was opening disposable instruments, and wipes.*

**Sources of information on HIV/AIDS.** In 2011, the SWs were receiving knowledge on HIV/AIDS from the following sources, in the order of their frequency (from the most frequent sources to less frequent): acquaintances, neighbors, school, ‘Darakchi’ paper, posters at polyclinics, series broadcast on ‘Yoshlar’ TV channel, during NGOs’ actions in parks ‘Babur’, ‘Ulugbek’ and on ‘Broadway’.

*“Several years ago there were actions devoted to HIV/AIDS. People whose friends had died of HIV/AIDS were hanging posters there. They don’t do this anymore.” FGD-SWs-37*

*“I saw a page on the Internet and heard about it on the radio on Day of HIV/AIDS.” FGD-SWs-40*

In 2011, there was access to basic knowledge and reminders about HIV, however, not detailed knowledge SWs need. The SWs mentioned difficulties in perceiving information in printed sources, its form and contents, obscure texts and terms, infrequent messages, and dull plots.

*“Most of posters are in Latin, and you cannot see anything about it on television.” SWs-35.*

*“There’s a ‘donut’ on the poster and HIV in the Uzbek language: ‘OITS’; or a girl is sitting and crying. What is all this about? Nobody knows.” SWs-30*

*“There are posters in the hospitals, but doctors wouldn’t tell you anything, saying: ‘Go there and read yourself’.” SWs-24*

*“We do not see a lot about it in the papers. On the radio - only on the Russian radio.” SWs-31*

In 2012, the rating of sources changed, and efficiency of information significantly improved due to the following reasons:

*FGD-SWs-HIVt-27 “The guys told me (outreach workers).”*

*FGD-SWs-HIVt-30 “They are giving us articles and brochures, inviting us to the ACR. Anonymous Consulting Rooms are just our rescuers. We need them very much.”*

*FGD-SWs-HIVt-28 “My ex-husband’s brother and his wife are PLWH. I visited the Anonymous Room, consulted with a psychologist. He told me everything and explained what I should do to protect myself.”*

*FGD-SWs-HIVt-38 “We are learning a lot once in three months at our meetings with PLWH at the TPs and AIDS Center.”*

**Knowledge about HIV risk groups.** Both in 2011 and в 2012, the SWs knew the following groups at risk to HIV infection: prostitutes, drug addicts (sharing needles when taking IDs), released convicts and health personnel.

*“I am now afraid to go to a polyclinic, or a hospital, or to a dentist. They say one has good chances of contracting the HIV infection there.” FGD-SWs-31*

The SWs still believe that all the population should be obliged to regularly have their blood tested for HIV, including doctors, nurses, police officers, taxi drivers, – all those providing services to people and contacting them directly.

The peculiarity of perceiving professional risk groups for SWs is a chance of meeting an HIV infected among their clients, or infecting a client by a CSW with the PLWH status.

### **SWs’ Knowledge, Attitudes and Behavioral Practices towards STDs**

The SWs showed quite a good level of knowledge on STDs: they know what gonorrhea, syphilis, trichomoniasis, etc., are, and that these diseases are curable. The SWs are aware of the necessity to use condoms, know where they can easily buy them or get them for free, – from any shop and drugstore up to TPs, and from outreach workers.

*“I was involved in prostitution, and contracted gonorrhea. I infected my husband. We came to Chilanzar KVD, did all the tests, and were treated at the KVD. Then my husband got syphilis. He was cured, too, at the KVD, because it was too expensive to pay a private doctor - about 200 thousand, - I am not earning that much for a whole night.” SWs-37*

*“There’s a Textile Factory hospital next to my house. They have an ACR there. I saw syringes, condoms there, and found out that one can get them for free.” SWs-30*

Some SWs were gaining knowledge about STDs at school, from doctors, at maternity homes, from TV programs on Russian channels.

*“These days, they have special classes at any school, starting from the age of 13. My son attends such classes at school.”* SWs-40

*“These classes are separate for boys and girls. Boys are being taught how to put condoms on.”* SWs-24

In 2011, the SWs admitted that when being sent by force to KVD for tests, they are trying to ‘improve’ the results, thus distorting the results.

*“We are washing ourselves with chlorine and toothpaste, so that they wouldn’t find any infection.”* SWs-24

In 2012, there were no such statements.

In 2011, the SWs stated that forced treatment at the KVD was of low quality, which is an obstacle to early and voluntary care seeking of the KVD services.

*“Very unfriendly atmosphere - bars like in a jail, and same attitude and meals. People commit suicides there. Girls were cutting their veins and hanging themselves.”* SWs-26, SWs-24, SWs-40

*“They would insert the biggest speculum, it hurts. And would call you saying: ‘You, cow, slut, bitch!’.”* SWs-24

*“I could not understand who that was in front of me - a doctor or an executioner.”* SWs-31

In 2012, there were no such statements made, – as a result of a better access to ACR services with relative services for STD diagnostics and treatment.

The SWs stated that besides VCT for HIV, outreach workers were telling them about STDs, – what that was and what the modes of transmission were, – and were taking SWs to ACR gynecologists for STD diagnostics.

*FGD-SWs-HIVt-45 “An outreach worker took a girl to an ACR because she wanted to save her money. If you come to a gynecologist you’ll have to pay. But here it’s free. She was told that she had trichomoniasis, and gave her free suppositories. She is still coming to visit this gynecologist. This doctor told her that she could bring her friends with her, and that they shouldn’t be ashamed.”*

## **Injection Drugs – Knowledge, Attitudes and Practices**

In 2011, the PWID were socially interacting with SWs. In 2012, SWs stated that many of the PWID had died of an overdose while yet young, having had AIDS or hepatitis before that, they infected their spouses because were sharing syringes, needles and other equipment.

The SWs mentioned that the number of PWID significantly dropped within the last years according to the following observations.

*“About 5 years ago, we could see groups of 5-6 gathering on the stairs of our building and jabbing with one and the same syringe. Children were hanging around and playing with these syringes. However, this is no longer happening in recent years.”* SWs-24 and SWs-40

*FGD-SWs-HIVt-30 “There’s less and less drugs in Tashkent in recent years, and that is why addicts are drinking vodka or switch to codacet. Heroin costs 40,000 Soums per dose.”* SWs-40

In 2012, the SWs stated that the practice of group consumption of IDs was still common due to the necessity of sharing expenses for purchasing IDs, however, groups became smaller (from 5-6 in 2011 to 2-3 in 2012), and PWID were trying to use individual syringes and needles, however, were continuing to share cups for preparing IDs and drawing IDs into syringes. Nevertheless, the SWs state that ‘the new generation’ of teen PWID ignores precaution measures.

*FGD-SWs-HIVt-25 “Very few of them are jaggig alone, - they don’t have enough money for that. My husband was jaggig with two of his friends.”*

*FGD-SWs-HIVt-30 “They’ve become very cautious, - each has his own syringe. They are now afraid of HIV. And if someone is infected he should tell them all that he is infected, otherwise they will cast him out of the group.”*

*FGD-SWs-HIVt-43 “Many addicts are coming to Trust Points to get syringes. They are giving syringes to them and telling them that they shouldn’t share syringes.”*

*FGD-SWs-HIVt-25 “Teen PWID in our district do not know that you can contract HIV and AIDS via needles. These are poor PWID, who are trying to save money on syringes, and are afraid of going to TPs for syringes, - they don’t know that it’s confidential there.”*

Like in 2011, the SWs believe that outreach workers should deliver the following information to teen PWID:

*“They should advertise it on television, radio, and in the press: ‘There is an AIDS Center somewhere, where you can have a blood test for HIV for free and anonymously, and nobody will know anything.’ And there should be phone numbers. The words ‘FREE AND ANONUMOUSLY’ should be written in capital letters. And mention that there are also (anonymous) rooms for PWID, STD and PLWH there.” SWs-40*

Like in 2011, the SWs believe that dependence on IDs can be overcome only if an addict himself really wants it, and people around help him strengthen and support his will. And, of course, they need employment and income. If you are poor it is going to be harder for you to overcome addiction.

The SWs are themselves willing to help and support PWID they personally know, and for that they deem as necessary the support of groups of ‘anonymous PWID’ organized by NGOs where PWID are already getting psychological support and communication.

*FGD-SWs-HIVt-25 “Vitya (an outreach worker) helped one of my acquaintances. I took him to Vitya, and he talked to him. He invited him to attend meetings with PLWH. This guy was ashamed for a long time to tell anybody that he had HIV, was avoiding women, and wouldn’t start a family. At these meetings he found out that all these PLWH had families, and he changed, and when he met a girl he told her in the very beginning: ‘I’ve got HIV. If you don’t mind we can continue our relationship’. Now, he would come to the AIDS Center and to TPs with Vitya to participate in their actions. He likes that.”*

## **VCT– Knowledge, Attitudes and Practices**

By 2011, some of the SWs admitted that they had never had an HIV test. The reasons were the following:

*“I don’t know where it’s located.” SWs-30*

*“I doubt that they will make a correct HIV test.” SWs-35*

Nevertheless, in the same 2011, other SWs, in general were positive about TPs and VCT, mentioning examples of voluntary and mandatory testing.



*In 2009, a vehicle came to our building, and my neighbor told me: 'They are doing blood tests for AIDS. Those who do the test are being given free mascara. They were all wearing clean white gloves. All was anonymous. They took my blood within 2 minutes, and gave me a phone number, and I called them seven days later, gave them the code and got the result.'* SWs-40

*"I had my blood tested when I was going to get married in Chor-Su, at the AIDS Center. They did not talk to me. But they used new gloves and a new sheet. I came to get the results, and they gave me the certificate, but I had to pay 10 thousand."* SWs-21

In 2011, the SWs mentioned the lack of quality services and guarantees of confidentiality, – when a customer is being assigned an anonymous code when coming for a blood test, however, if he is diagnosed with HIV he has to show his passport in which they are making a note about his HIV status, and are submitting information to his district police department and polyclinic.

In 2012, the SWs did not bring up the above mentioned facts, and stated the following, underlying outreach workers' role in the accessibility of different services at TPs and AIDS Centers:

*FGD-SWs-HIVt-43 "There are brochures at polyclinics which have addresses and phone numbers of Trust Points."*

*FGD-SWs-HIVt-45 "If I need syringes or condoms today I would call the ACR, come to them and get syringes or condoms. We all know their phone numbers. If nobody picks up the phone at the ACR I would call the outreach worker's cellular phone. He would always answer."*

*FGD-SWs-HIVt-42 "I generally come to Julia at the Trust Point a couple of times a month. She would give me advice and condoms."*

In 2011, the SWs said that they were not advising their sexual partners and clients to do an HIV test since they were afraid of losing them, or of being blamed for possible infection.

In 2012, the SWs started to recommend VCT, – though to their regular partners, – because they were much surer about the confidentiality of VCT and had much more trust in TPs.

*FGD-SWs-HIVt-45 "Outreach workers called me and told me about the VCT action, and I suggested it to my regular partner. He said immediately: 'Yes, let's go.'"*

*FGD-SWs-HIVt-33 M: "However, we can't recommend this to our occasional partners, because they would become suspicious and think that we are infected."*

*FGD-SWs-HIVt-30 "They would tell you that they are 'clean' because they have wives. And if you suggest this to them this will mean that you are like that, too."*

Both in 2011 and in 2012, not all the SWs knew about the 'window period', however, all of them knew about the necessity of regular testing for HIV, and some of the SWs mentioned their regular use of VCT services.

*FGD-SWs-HIVt-30 "As our outreach workers explained to us, if a person catches an infection it might not be revealed within half a year or even more."*

*FGD-SWs-HIVt-28 "I am going for VCT every month."*

*FGD-SWs-HIVt-32 "Me - every six months."*

The SWs know that in case they hide their HIV infection they will have to buy medicines for ART treatment (20 thousand Soums for a course of 20 medicines), however, if you register with an AIDS Center you will be able to get free medicines via outreach workers.

## SWs' Needs and Recommendations

In view of the above mentioned, we can conclude that the SWs' following suggestions obtained in 2011, in general, were taken into consideration (the contents and forms of information they needed) and implemented by 2012:

*"I'd like to obtain this knowledge in the form of a discussion like this one (the FGD)." SWs-31*

*"They should organize meetings with real PLWH." SWs-30*

*"Stories from real life are better than lectures. Meetings with PLWH would be useful." SWs-40*

*"They should also hand out brochures at these meetings with phone numbers of Trust Points where one can come to ask questions and do tests." SWs-31*

In 2011, the SWs suggested that only printed information should be disseminated in mahallas.

In 2012, although the SWs regarded mahallas as a source of stigmatization and the reason of the breach of confidentiality, they think it necessary to disseminate knowledge and form attitudes to PLWH among formal and informal mahalla leaders in the form of meetings with real PLWH via ACR employees. The meetings with real PLWH will help reduce the occasions and intensity of stigmatization and discrimination of PLWH at places of their residence. This approach is based on the SWs' statements.

In 2011, the SWs believed that VCT was facing such an important obstacles as discrimination and stigmatization of PLWH, as well as the possibility of their forced treatment.

2011 quotations:

*"My friend-doctor works for an AIDS Center. She is outraged at the voluntary principle of treatment, and says that treatment should be forced, and PLWH should be isolated in some remote place so that don't spread HIV." SWs-31*

*"An HIV patient can come to any polyclinic. They should have their own special clinics." SWs-34*

2012 quotations:

*FGD-SWs-HIVt-27 "One of my acquaintances was diagnosed with HIV, and after that she was ousted not only from her mahalla but from her family as well."*

*FGD-SWs-HIVt-28 "I think HIV has become common these days, and such cases are rare."*

In 2012, the SWs did not make such statements, and SWs mentioned reduced stigmatization among health personnel towards PLWH.

Both in 2011 and in 2012, the SWs would like to have better quality services such as consultation, diagnostics and administrations without breach of confidentiality. Due to the low quality of available services at public institutions they have to apply to private clinics with expensive services.

*FGD-SWs-HIVt-35 "If I come to a gynecologist, and, say, I've got a venereal disease. The doctor will immediately start telling everybody about that. Not only the whole polyclinic will be informed but the whole territory, and the whole district."*

*FGD-SWs-HIVt-30 "There were such cases with our neighbors, it's true. They do not observe confidentiality at these polyclinics."*

*FGD-SWs-HIVt-25 "I was giving birth at the N. maternity home, and they diagnosed me with a venereal disease. They informed my mother-in-law and my husband. However, mother-in-law made a row. She took my doctor and me, and we went to the KVD, and I did my test there."*

*Then the doctors told me: 'Sorry, it was a mistake'. But I lost my breast milk because of all this.*

*FGD-SWs-HIVt-46 "I did a smear test three years ago, and they found trichomoniasis. I had called in a doctor, and she came and offered me either a paid or a free test. She said: 'If you pay it will be anonymous, but if you want it free we will send the test to the KVD'. I gave her money. Then I went to an acquaintance doctor, and cured within a week."*

In 2011, the SWs believed that there should be more conveniently located places where one could get VCT with minimum financial or time spending, – like, for example, at TPs.

*FGD-SWs-HIVt-27 "You have to wait in long lines at the AIDS Center."*

*FGD-SWs-HIVt-42 "Yes, there are long lines of people there. It's better and easier to go to an Anonymous Consulting Room."*

The SWs believe that the disseminated information should cover not only information on HIV and STD risks, availability of VCT at TPs in the cities where information campaigns are being carried out, but also information about TPs in the other cities which one can visit anonymously, without showing any identity documents, in case he/she happens to be in any other city while needing VCT.

The SWs' further needs are reflected in the following recommendations and questions:

*FGD-SWs-HIVt-27 "There is a polyclinic in the mahalla where all the residents are coming. However, there's no Anonymous Consulting Room there."*

*FGD-SWs-HIVt-30 "Our clients are saying that there are no such Anonymous Consulting Rooms in the provinces, they have only been opened here. Thank God they are here!"*

*FGD-SWs-HIVt-30 "They don't have enough condoms at TPs these days, and those that they are giving out are not quite a good quality, - some would break frequently."*

*FGD-SWs-HIVt-34 "I used to receive condoms from S. at the Anonymous Consulting Room. My acquaintance girls asked me bring them for them. I asked him how to prevent infection if they break even if you are putting on two of them?"*

*FGD-SWs-HIVt-28 "SWs need moral and psychological support." (and then they mention improvement of such support. Moderator)*

*FGD-SWs-HIVt-46 "I would like to communicate with each other more frequently, and with outreach workers, - for example, with Julia, who would always give you good advice."*

*FGD-SWs-HIVt-28 "It's good even if you manage to meet and talk to her three times a year."*

*FGD-SWs-HIVt-30 "We would meet with her more frequently - once a month."*

*FGD-SWs-HIVt-38 "Those (SWs) who are sick need good nutrition and vitamins, but they don't have any occupation."*

Both in 2011 and in 2012, the SWs mentioned the need to change their clients' attitude towards the practice of using condoms, because they are subject to the risks of getting infected or infecting their clients. The SWs themselves, although trying, still cannot persuade their clients make it a rule to use condoms. Both in 2011 and in 2012, the SWs stated that about 70-80% of their clients were refusing to use condoms. There should probably be information campaigns to introduce the skills of using condoms not only via SWs but rather via other channels, focusing on the following situations when clients are refusing from condoms, and the so-called 'trust' of SWs of them:

*2011 quotations:*

*“There are at least 70% of those who want this without any ‘devices’. And we then have to visit all these doctors.” SWs-31 and SWs-40*

*“I can ask or suggest, but it’s men who make the decision, because they are paying, and you can’t put on a condom by force.” SWs-31*

*“Under the influence of alcohol, people would usually lose their control. If their ‘little head’ is active, their head is sleeping.” SWs-31*

*“PWID are safe to have sex with. They can do ‘this’ for hours without coming (without ejaculation).” SWs-24 (Such PWID and SWs should be informed that these ‘hours’ of activity may result in abrasions and injuries in partners, contact with blood and high risks of HIV infection)*

*“There are many men and women who are coming to Tashkent these days from provinces. They are not aware of the HIV and STD risks, and are contracting infection here. For example, in the Kuyluk or Farkhad bazaars.” SWs-30 and SWs-35*

2012 quotations:

*FGD-SWs-HIVt-32 “Very few would agree for a condom - about 20%.”*

*FGD-SWs-HIVt-30 “They would say that they don’t feel anything with a condom.”*

*FGD-SWs-HIVt-28 “I think they should be educated, these men. And we are getting these infections because of them. Many men are traveling to Russia to work, and are catching these diseases there.”*

*FGD-SWs-HIVt-30 “They would come back from there and have sex here without condom.”*

In 2012, the SWs mentioned that their knowledge of the necessity of using condoms when servicing clients significantly improved after meetings with outreach workers.

*FGD-SWs-HIVt-45 “I rented my apartment to girls (respondent-pimp. Moderator’s note). Outreach workers asked me to let them talk to them. They came and started to tell them the following: ‘You are negotiating with a man who offers you 100 dollars for sex without a condom. You are telling him that you won’t agree to lie down with him without a condom. Then he says that he will give you 150 dollars or will go away, and you agree. Sometime later you realize that you’ve caught a disease. You have to do tests, however, not at Trust Points but at some other places. You have to pay a certain amount of money for the tests. Then doctors will prescribe medicines and treatment to you. All in all, it will be more than 150 dollars in the end. So, is it worth doing that?’ This conversation made the girls think hard. They decided to use condoms. But before, if someone would tell them: ‘If I give you a lot of money will you agree?’ they would happily agree: ‘Sure, I will!’”*

## **PLWH KNOWLEDGE, ATTITUDES AND PRACTICES**

### **PLWH composite profile**

- Age – 20-55;
- Gender – men and women;
- PWID, SWs or not;
- Married to PWID, PLWH, PLTB or to healthy spouses;
- Having children with HIV or without HIV status;

- Employed mostly in the service sector, or unemployed;
- Income: low or medium.

In this Section we are describing the peculiarities of PLWH's knowledge, attitudes and practices different from those described in the previous Sections of the Report, – not to repeat the same in this Section.

### **Knowledge and Attitudes towards HIV**

The PLWH's knowledge of HIV/AIDS is quite comprehensive, since they have had experience of using VCT and/or treatment of HIV. They know what HIV is, how it differs from AIDS, what the modes of transmission are, know which facilities should provide which types of assistance – e.g. VCT, ART, giving syringes and condoms. The PLWH would share their opinions with each other on the quality of this assistance, on the ART process, on the medications and types of food one can boost his immunity, what these or those CD4 indicators mean, and what to do depending on these indicators.

*“A person with the HIV status would pay attention to everything related to HIV.” FGD-F-PLWH+SWs-28-son with HIV status*

*“Everybody is talking about HIV and AIDS.” FGD-PLWH+PWID-M-32*

In 2012, as well as in 2011, the PLWH mentioned that the population and some MARPs do not understand the difference between HIV and AIDS, therefore using the term AIDS instead of HIV. Since AIDS is a more advanced stage of the disease than HIV this attitude to AIDS as a phobia is being shifted onto HIV.

In 2011, some PLWH stated that signs of TB are the signs of HIV as well. In 2012, there were no such statements.

The PLWH know that it is impossible to tell by a person's looks or state if he has HIV or not, because this disease can only be determined by ELISA (enzyme-linked immunoabsorbent assay) (in the other MARPs these terms were not mentioned).

The PLWH are aware of the 'window period', since they have used VCT more than once, including for double checking the results of their previous tests.

### **Knowledge and Attitudes towards Infection Prevention Measures**

As before, the PLWH know that HIV prevention is based on avoiding contact with PLWH's blood, with instruments that might have PLWH's blood, – both at home and at health facilities, – and the PLWH need this knowledge, first of all, to protect people around them against the infection.

*“First of all, when I found out that I had HIV, I started to inquire how this could affect my family members. I was explained that we need separate personal hygiene items: individual tooth brushes, etc.” FGD-PLWH+PWID-F-30*

As before, female PLWH believe that the number of women with HIV has been increasing, as well as the risks for their children, therefore, when speaking of protection of the fetus against HIV, they stated that the safest method of birth is the Cesarean section.

*“I was told by a friend that the N. maternity home would close frequently because there are a lot of HIV-infected women giving birth there. My doctors told me that it's better to have a Cesarean section.” FGD-F-PLWH+SWs-28-son PLWH*

The peculiarity of PLWH's knowledge in 2012 was that they mentioned all HIV prevention means, and that the law makes PLWH responsible for non-adherence to the measures of protection of the other people or for their intended infection.

*FGD-PLWH-M-HIVt-45 "One should use disposable syringes."*

*FGD-PLWH-M-HIVt-33 "Everybody should use condoms, - even with your wife."*

*FGD-PLWH-M-HIVt-40 "It's not safe to share instruments, razors, etc."*

*FGD-PLWH-M-HIVt-55 "Toothbrushes."*

*FGD-PLWH-M-HIVt-48 "We are obliged to warn everybody about our status. We signed a document."*

*FGD-PLWH-M-HIVt-52 "You can be imprisoned for up to 10 years for having infected someone."*

### **Knowledge and Attitudes towards Associated Illnesses**

The PLWH, – as before, – know that TB is a serious illness associated with HIV/AIDS, which looks like a common cold or it's complication in the beginning.

The PLWH, – as before, – believe that TB is one of the most common comorbidities for PLWH.

*FGD-PLWH-F-TBt-33 "It's not necessarily that PLWH should have TB, however, these days there are many TB patients among PLWH, and this tuberculosis is a smear-positive form of tuberculosis."*

In 2012, the PLWH gave quite a long list of diseases that PLWH are vulnerable to.

*FGD-PLWH-F-HIVt-46 "Pneumonia."*

*FGD-PLWH-F-HIVt-45 "Cancer, sarcoma."*

*FGD-PLWH-F-HIVt-28 "Chronic diarrhea. Persistent fever."*

*FGD-PLWH-F-HIVt-46 "Candidosis."*

*FGD-PLWH-F-HIVt-33 "Stomatitis."*

### **Sources of Knowledge**

In 2011, the PLWH mentioned a lot of sources of obtaining knowledge on HIV: doctors at the AIDS Center and at the Virology Institute, messages on TV, radio and the Internet, brochures, booklets.

*"The first time I learned about HIV was from a conversation with an infectiologist at the AIDS Center. He also told me about TB." FGD-F-PLWH+SWs-38*

*FGD-PLWH-F-HIVt-42 "We read newspapers. I work at a hotel, and I've got a TV at my work place. After I found out about my status I started to watch programs about HIV. They used to show many of them on cable TV. Also, in programs devoted to health issues."*

*FGD-PLWH-F-HIVt-46 "I myself participated in programs of our Uzbek TV."*

In 2012, the PLWH were mentioning more frequently outreach workers, NGOs, AIDS Center and ACR employees as sources of knowledge, since they needed not only general knowledge but rather special knowledge, preparations, syringes, condoms, and psychological support.

*FGD-PLWH-F-HIVt-46 "I personally learned about associated illnesses from social workers - volunteers. In the beginning it was 'Ishonch va khayot'. Later, there was another organization, but I don't remember the name."*

*FGD-PLWH-F-HIVt-45 “I heard about the Project ‘Dialog on HIV, AIDS and Tuberculosis’. There, people like us (PLWH) were speaking about HIV and TB.*

In 2011, one of the PLWH said that a doctor at the Virology Institute had told him that HIV is air-communicable. Some PLWH mentioned the low quality of doctors’ services, too. In 2012, there were no such statements, and the PLWH mentioned the improving quality of doctors’ services at polyclinics.

*FGD-PLWH-F-TBt-32 ‘In the past, doctors themselves did not know everything about HIV/AIDS. Later, - after 2007, - as a result of regular training, doctors’ knowledge improved. Doctors’ attitude towards PLWH has changed not only at the AIDS Center but at polyclinics as well. For example, at my polyclinic, the gynecologist knows that I’ve got HIV, and if she sees me in the corridor she immediately calls me in ahead of line. She never asks me to bring gloves but uses her own.*

In 2012, the PLWH mentioned that messages in mass media about HIV, posters and messages in social ads had become less informative.

*FGD-PLWH-M-TBt-20 “They would just write: ‘Beware of HIV’, and that’s all.”*

*FGD-PLWH-M-TBt-37 “They would show two men and one syringe, and that’s it.”*

### **Voluntary Consultation about HIV – Knowledge and Practices of Usage**

In 2011, some of the PLWH stated that they had never heard about Voluntary Consultation and Testing. This statement contradicted the actual situation, since all the PLWH had used services of AIDS Centers and Anonymous Consulting Rooms, and Friendly Services Rooms where they were provided with consultation, testing, syringes and condoms. The most probable explanation of this contradiction is the fact that the PLWH simply did not know the term ‘VCT’. In 2011, the PLWH had controversial opinions about VCT. On the one hand, they said that they were being provided with consultation and testing, but on the other hand, they mentioned the lack of tact and psychological skills on the part of AIDS Center personnel when being told about their HIV status.

*“After hospitalization, they diagnosed me with HIV, and came to the AIDS Center, but they told me to come the next day. I came, and the psychologist talked to me about something for about half an hour. I didn’t see a doctor. They only gave me a paper to sign that said: ‘If you infect somebody you will be sentenced for 10 years’. That is all, you can go, you’ve been registered.” FGD-PLWH+PWID-M-32*

*And I was told to read their brochures and that if I infect someone I could put in jail.” FGD-F-PLWH+SWs-38*

In 2012, some of the PLWH mentioned the high quality of VCT at AIDS Centers and at TPs, however, the other did not know about the accessibility and the quality of services at AIDS Centers.

*FGD-PLWH-F-HIVt-46 “There’s a psychologist at the Republican AIDS Center who can give you free consultation.”*

*FGD-PLWH-F-HIVt-33 “There’s a psychologist at the AIDS Center in Chorsu, too, and a TB specialist.”*

*FGD-PLWH-F-HIVt-33 “She gave me a moral support.”*

*FGD-PLWH-F-TBt-32 “I was diagnosed with an HIV status 5 years ago. My son is 8 years old, and he is HIV infected, too. I’m doing my best to survive. When I found out that I and my son had HIV I had a terrible depression. I came to the Center AIDS and to Anonymous Consulting Rooms to learn everything about this disease, and I calmed down. If somebody of*

*my co-workers would say, for example: 'Have you heard that he's got HIV?!', I would now ask them calmly: 'So what's wrong with that?'"*

### **Practices of Seeking and Following ART**

As before, some of the PLWH are taking support therapy and treatment of associated illnesses, the other would terminate treatment sometimes trying to replace it with diversified and high calorie diet rich in vitamins. The third would just refuse treatment at all. The reasons of this behavior are the following:

*"Conditions are terrible at the Virology Institute, very little attention, lack of medicines."*  
PLWH-SWs-F-34

*"I found out that I had HIV three years ago. But I don't take any treatment, because I know a lot of those who felt even worse after treatment."* FGD-PLWH+PWID-F-28

*"They've opened a room for HIV infected, where they can see an ENT doctor, a cardiologist and a dentist. They've renovated the room nicely, however, it was not always open but only when they wanted, and now it's closed all the time."* FGD-PLWH+PWID-M-32

The PLWH still have contradictory opinions about ART. Some of them state that they are receiving treatment regularly and that it helps them survive, while the other are saying that not all the necessary medicines are always available, or that they are available not for everybody, and that they have to buy some medicines (not for ART) themselves.

*"This treatment helps you live longer."* FGD-PLWH+PWID-F-30

*"There are medicines for ART, however, not always. You can't find either this or that preparation."* FGD-PLWH+PWID-M-32

The PLWH mention cases of supporting PLWH with ART courses, however, are concerned that some PLWH with AIDS do not have access to ART.

*FGD-PWID-F-HIVt-37 "They (doctors) are already not practicing ART. If you remember, R. Had a younger brother. He died recently of AIDS. Doctors would give pills only to those who have been on this treatment for a long time, because they don't have supplies of these medicines anymore. And one cannot buy these medicines for ART anywhere."*

### **Risks of Breach of Confidentiality, Stigma and Discrimination**

In 2011, the PLWH mentioned high risks of breach of confidentiality at all levels of health facilities that are exchanging their data on these or those PLWH both for prevention measures to protect healthy population and for monitoring of the situation with PLWH.

In 2012, the PLWH confirmed that there were cases of breach of confidentiality, stigma and discrimination, however, mentioned that their number had been reducing.

*FGD-PLWH-F-TBt-29 "My family members know that I've got HIV. But when we talk with our neighbors in the street I sometimes hear them saying: 'You know, this or that person has got HIV!'. And I'm thinking: 'What would they say about me if they find out that I'm HIV infected?!'"*

*FGD-PLWH-F-TBt-32 "Your family members are supporting you. But mine have cast off their grandson. That is why I would like to live separately. By the way, my son is receiving ART."*

*FGD-PLWH-F-HIVt-46 "When I worked as a housekeeper, an acquaintance of mine, - HIV infected, too, came to that house once. He turned out to be my employer's relative. And he told him: 'Whom have you employed?! She's HIV infected, I know her!', and I was fired after that."*



*FGD-PLWH-F-HIVt-46 “I explained to my family members and neighbors what kind of a disease that is, and that I am not contagious as long as they do not use my personal items. I told them that so that they wouldn’t be afraid of me; and that I am the same as them. It took years for me to make them understand that. Now everything is fine.”*

*FGD-PLWH-F-TBt-32 “My son doesn’t know that he’s got HIV. He’s taking pills and ART, and thinks that it’s vitamins. Nobody knows at his school that he is HIV infected. It’s being kept confidential.”*

The PLWH believe it necessary to improve the efficiency of information campaigns to reduce stigma and discrimination.

*FGD-PLWH-F-TBt-32 “They should carry out educational work among the population. For example, Anonymous Consulting Room employees could gather mahalla residents and explain to them what HIV, AIDS and tuberculosis are, and how to live with PLWH and PLTB.”*

In 2012, after the PLWH efforts aimed at protection of their rights, both doctors’ and neighbors’ and their family members’ attitude toward them became more tolerant. Both in 2011 and in 2012, the PLWH were saying that their acquaintances were trying to help them keep their jobs and families, because they could see living persons in front of them rather than an abstract infection. It is clear that to reduce the level of stigmatization, the PLWH should be shown in information campaigns as ‘more human’, seen through the prism of a fate of a certain individual.

*FGD-PLWH-F-TBt-32 “One of my doctors at the polyclinic told my district doctor that I was HIV infected. That district doctor came to my house and started asking my family members how they were living with me and whether they knew that I had HIV?! However, all my family members knew everything about me. I came to the polyclinic Head Physician and required that he fired that doctor for breaching confidential information. He called her in even before I left and fired her under the Article that punishes breach of medical ethics.”*

### **Knowledge and Attitudes towards TB**

Risk group for TB mentioned by the PLWH were still not only ‘we ourselves’ but ‘any person’. They regard regular medical checkup necessary not only for themselves but for all the population, without exception.

The PLWH still have a phobia of TB, however, in 2012, the PLWH mentioned cases when their fear was minimized or overcome after consultation with NGO outreach workers, ACR and the AIDS Center employees.

*FGD-PLWH-F-TBt-29 “Last year I lost my husband, and I would like to go for a tuberculosis test, but I’m ashamed. And, first of all, I’m afraid.”*

*FGD-PLWH-F-TBt-29 “Rano apa helped me understand that you shouldn’t be afraid or give up hope. You should continue treatment. She said it doesn’t mean that you’re going to die, and that in most cases one can cure himself. They can even cure cancer these days. And tuberculosis, too. The main thing is to start treatment promptly and eat well.”*

Some PLWH were aware that in 2012, within the governmental HIV programs, PLTB have the right for, and should receive, free services at governmental health facilities. However, the other PLTB do not yet know about that.

*FGD-PLWH-F-TBt-32 “I was told by outreach workers that those with HIV or tuberculosis should be provided all services for free at any family polyclinic, because this is being financed by the government. For that, one should see an infectinonist who is to certify that you’ve got this disease. Then this paper is to be signed by a Head Physician or his deputy.”*

*FGD-PLWH-F-TBt-32 “Many people do not know their rights and therefore do not fight for them.”*

The PLWH continue to sometimes face difficulties in receiving services at governmental health facilities.

*FGD-PLWH-F-TBt-43 “No, nothing is free at our polyclinic. An X-ray is 10,000 Soums.”*

*FGD-PLWH-F-TBt-46 “I made a row at my polyclinic because of that. Only after Jakhangir with Julia (outreach workers) had come with me to our polyclinic they told me: ‘OK, Opajon, come tomorrow, and we will do everything you need’. I am coming to the polyclinic the next day but they are telling me to go to Hospital #16 where they will do an X-ray for me for 25,000 Soums! Where can I find this money to do an X-ray each time?!”*

Due to these difficulties, the PLWH prefer to get services, – and are receiving them, – through outreach workers who help them with access for VCT and DOTS. They also state that outreach workers advise them to get related services – legal, psychological, health, etc.

*FGD-PLWH-F-TBt-44 “Outreach workers offered me legal, psychologist’s and doctor’s services.”*

*FGD-PLWH-M-TBt-52 “For me it’s easier to turn to them (outreach workers) than go to the polyclinic. They never have films.”*

*FGD-PLWH-M-TBt-43 “You’d better go to outreach workers. They do it promptly - a vehicle comes and everything is done soon.”*

*FGD-PLWH-M-TBt-52 “One of my acquaintances was recently diagnosed anonymously at the ACR, and when the outreach workers had his test ready they took him to the TBPC who provided free assistance for him.”*

*FGD-PLWH-F-TBt-32 “With the help of the outreach workers I was included to a DOTS program. There’s a DOTS corner at each polyclinic now, with a lot of literature on tuberculosis. There’s a special nurse responsible for the DOTS program. She started to read us this literature.”*

*FGD-PLWH-F-TBt-43 “With their help I can, for example, go to a gynecologist for consultation, or to any other doctor. Besides, they are helping us to get certain medicines.”*

*FGD-PLWH-F-TBt-43 “For DOTS, for example.”*

*FGD-PLWH-F-TBt-43 “They are helping us to get an administration for DOTS or ART.”*

*FGD-PLWH-F-TBt-29 “They would always keep everything confidential.”*

*FGD-PLWH-F-TBt-46 “They provide a very good psychological support.”*

*FGD-PLWH-F-TBt-46 “I’ve been seeing a psychologist for three years already.”*

Speaking of outreach workers, the PLWH would emphasize the accessibility and high quality of services at TPs.

*FGD-PLWH-F-TBt-29 “One would rather go to an ACR, - because at the tuberculosis dispensary they would send you here and there, while at an Anonymous Consulting Room they would always try to do everything fast and with minimum effort.”*

*FGD-PLWH-F-TBt-43 “Everything is anonymous at an Anonymous Consulting Room, and they would give you a referral for free services.”*

*FGD-PLWH-F-TBt-33 “Besides, nobody would receive you without a passport. But at an Anonymous Consulting Room, they would receive you even if you don’t have a passport. They would provide any other assistance to you.”*

*FGD-PLWH-F-TBt-33 “I’ve been regularly coming to the Anonymous Consulting Room to get condoms and syringes.”*

*FGD-PLWH-M-HIVt-49 “They are now providing us with more information at TPs, - how to treat our disease, how to overcome (addiction).”*

*FGD-PLWH-M-HIVt-55 “It’s more interesting now.”*

*FGD-PLWH-M-HIVt-48 “We would gather from time to time, we’ve got our social circle now. We share our experience with each other. At the New Year’s eve, we were preparing presents.”*

Some PLWH regard the quality of services at the TBPC as low, and some services paid, however, at the same time, they are mentioning the improvement of this quality.

*FGD-PLWH-M-TBt-44 “I stayed at a hospital in Nurabad. It was quite good there. However, I had to buy some medicines myself (not DOTS preparations) because I was willing to cure myself.*

*FGD-PLWH-M-TBt-44 “They are giving you Isoniazid, Ethambutol, Tubazidum - all those necessary preparations.*

*FGD-PLWH-M-TBt-45 “They don’t always have Rifampicin. You have to buy it.”*

*FGD-PLWH-M-TBt-34 “Too many TB patients, and treatment is prolonged, hospitals are packed, that is why some patients have to pay money to get hospitalized.”*

*FGD-PLWH-M-TBt-37 “Even if you have money some facilities are horrible. My younger brother stayed at such a hospital, - the third floor, building #3, - the walls in the wards were peeling, because they hadn’t had renovation for a long time.”*

*FGD-PLWH-M-TBt-45 “Building #3 is where former convicts are mostly being treated.”*

*FGD-PLWH-M-TBt-43 “However, it’s very nice in Building #1, - they treat those there who have paid.”*

### **Knowledge, Attitudes and Practices towards STD**

The PLWH are still quite aware of STDs, and mentioned their names, symptoms, modes of transmission and ways of prevention, specifically condom use. The main source of knowledge for PLWH was their own experience and their acquaintances’ experience. By 2012, they added outreach workers and AIDS Center and ACR employees as sources of knowledge.

The peculiarity of experience with STDs for some PLWH prior to getting infected was their disregard of condoms, further treatment of STDs at their ‘acquaintance’ doctors without registration of diseases, or self-treatment.

Some of the SWs with HIV mentioned other PPDs beside condoms, – they had probably learned about them while working abroad or from those who had worked abroad.

Condoms are accessible everywhere – at drugstores, in any store all day round, as well as free condoms at AIDS Centers, TPs and from outreach workers.

**Practices of using PPD.** The PLWH always insist on using condoms, and wouldn’t allow sex without condoms with a healthy partner.

*FGD-PLWH-F-HIVt-33 “I insist if a man refuses from a condom.”*

*FGD-PLWH-F-HIVt-28 “I refuse from sex (in this case).”*

Nevertheless, HIV prevention means mentioned by PLWH are, first of all, condoms and refusal to share syringes when taking IDs together with ‘AIDS carriers’ (the name for PWID who have HIV).

### **Knowledge, Attitudes and Practices towards IDs**

As in all the other groups where we discussed the issues of IDs, the PLWH mentioned the absence, or reduction, of cases when syringes or needles are being shared, however, they stated that such cases do occur among ‘the new generation’ of teen PWID.

*FGD-PLWH-F-HIVt-33 “These days, everybody is using its own syringe.”*

*FGD-PLWH-F-HIVt-46 “It’s because one can get them for free.”*

*FGD-PLWH-M-TBt-45 “I know that I can always come to a TP and get enough syringes for a week. But these teens do not know that. A syringe costs 150 Soums at a store. They think they would rather save these 150 Soums.”*

*FGD-PLWH-M-TBt-43 “It’s because there’s no information these days on the danger of contracting HIV if you are using one and the same syringe.”*

The SWs with HIV mentioned that group usage of IDs with one syringe had significantly dropped as compared to 5-10 years ago, and that it’s common practice among PLWH these days to use individual syringes.

*“If a person who is jabbing with me in a group is HIV infected, - which happened a couple of times, - I was using my own (syringe).” FGD-F-PLWH+SWs-28-son with HIV*

As before, some PLWH stated that it was a risk to share syringes and needles only, and you are not subject to a risk of contracting HIV or hepatitis C if you are sharing a cup with solution and the solution itself.

### **PLWH Needs**

The PLWH need the following forms of assistance.

Specialized medical assistance to PLWH. The PLWH believe that due to their compromised immunity, they are vulnerable to diseases, and need more assistance than general population, that is why they need to be provided with contact information on certain health facilities that could provide them specialized assistance as to PLWH.

*“Nobody would come and visit them at home. Not even once. Never.” FGD-PLWH+PWID-M-32*

*FGD-PLWH-M-HIVt-49 “I cannot work. If I’ve run around for one day the next two days I can hardly make my way to the bathroom.”*

*FGD-PLWH-M-TBt-37 “If I get sick, I don’t even know where to turn to, whom to call!”*

*FGD-PLWH-F-TBt-29 “Doctors themselves should come and visit those PLWH who are too weak. Some of them are so sick that they cannot go out. They can hardly walk, and do not have money for a trip to a doctor.”*

**Need to participate in information campaigns and outreach workers’ activities.** The unemployed PLWH are willing to personally participate in information campaigns, and work as an outreach workers.

*FGD-PLWH-M-HIVt-45 “I would really like to help people, - with all my heart.”*

*FGD-PLWH-M-HIVt-all. “We would like to work as outreach workers.”*

*FGD-PLWH-F-HIVt-46 “If I get into a taxi, and the driver starts hitting on me I would tell him immediately that I’m HIV infected and explain to him what that is. I participated in a TV program, too. They showed me on TV for half an hour. I didn’t cover my face. They broadcast this program on DTV, Channel 3 - ‘Tashkent’.”*

*FGD-PLWH-F-HIVt-46 “They should train such people like me, for example, or S., - who could openly tell about our diseases, - and then promote them at meetings schools, work teams, mahallas. For example, I will come to a school and say: ‘Hi, children. I’ve got HIV infection. I’ve come here to tell you about this disease’. So that people could see me alive, and learn that, first of all, it’s a real disease. And, secondly, that we are the same people as them.”*

*FGD-PLWH-F-HIVt-33 “Because people think that HIV means the end of your life”.*

**Reimbursement of transportation expenses.** The PLWH state that, as their experience shows, and because outreach workers are not always available, TPs and NGOs could help PLWH by paying for their trip to TPs and health facilities, since PLWH do not usually have high income, however, they have financial needs to pay for transportation between facilities.

*FGD-PLWH-F-HIVt-46 “These days it’s even hard for healthy people to get somewhere. Z. came with me today, and paid for the trip, but tomorrow she won’t be able to do that, because she won’t have money for that. In most cases, it’s due to financial problems that we are not able to visit TPs frequently.”*

*FGD-PLWH-M-HIVt-44 “I used to get ART preparations at the Republican AIDS Center. Then they all were moved to the Tashkent AIDS Center. This is very inconvenient. It’s too far, that is why you have to ask permission to leave work early.”*

**Reduced access to some services.** Some PLWH state that the range of services for them, – free condoms, syringes, psychologists, medicines, replacement therapy, ART, etc., – has been reduced. The PLWH would like to have access to replacement therapy again, since their health does not allow them to look for hard-to-get heroin or switch to Codacet.

*Replacement therapy was necessary for our teens. So that they didn’t look for cheaper heroin.”*  
*FGD-PLWH+PWID-F-32*

*PLWH+TB-M-39 “To kick it, one needs replacement therapy. There were pills and syrup between 2006 and 2009. Pills could be taken out, but not syrup. People could come and take some syrup to relieve their condition and not to jab again. This will make it less probable that they’ll infect somebody.”*

*FGD-PLWH-F-HIVt-28 “In the last year, there was less assistance to us. No condoms, which is the worst problem.”*

*FGD-PLWH-F-HIVt-46 “Much less help. No psychologists, no syringes.”*

*FGD-PLWH-M-HIVt-45. “They should allow to use Methadone again. When that project was closed many people died. In 2002, I was diagnosed with HIV, and then I did a test again. I stopped doing all this because I felt better. Then I saw my girlfriend doing this and feeling better, and I started it again. They offered me viral therapy, and all the indicators started to improve. Between 2006 and 2009, I participated in the Project. I would come, put my signature and took all the medicines. I felt like I was absolutely healthy. I was working. Everything was fine. But when they closed the Project, I didn’t know what to do. The only way was to buy drugs again. No such medicines that would help you. I am taking ART now.”*

*FGD-PLWH-M-HIVt-45 “It’s because if you’ve refused ART once they wouldn’t offer it to you again.”*

*FGD-PLWH-M-HIVt-49 “They wouldn’t provide ART. You can go and ask them, and we’ll see what they will tell you! They don’t have enough preparations.”*

*FGD-PLWH-M-HIVt-40 “They would all tell you that they have medicines but you have to wait for your turn. It’s for a whole year that we’ve been told that.”*

Need in housing and work in some community for PLWH.

*FGD-PLWH-F-HIVt-all “It would be nice if they have a special town for PLWH. We could be useful there, and entertain ourselves, and get treatment, and work.”*

*FGD-PLWH-F-HIVt-45 “Yes, and children would feel themselves comfortably there. Now children with HIV are being avoided by other children as if they are leprotic.”*

*FGD-PLWH-F-HIVt-33 “It would be better if there were special kindergartens for children with HIV, because they can scratch each other and spread infection.”*

Psychological support by society and specialists.

*“HIV or AIDS means death, - it’s like you are walking in the street and all of a sudden is being hit by a car!” FGD-PLWH+PWID-M-32*

*“One would like to live longer.” FGD-PLWH+PWID-F-28*

*I want hope, only hope. I would like to know what they are doing there about it, - these scientists.” FGD-F-PLWH+SWs-38*

*FGD-PWID-F-HIVt-30 “We need care and love. In this case we won’t be scared to have this disease.”*

*FGD-PWID-F-HIVt-35 “Care on the part of relatives, - so that they (PLWH) did not feel abandoned.”*

*FGD-PWID-F-HIVt-37 “I don’t know, - I’ve got many acquaintances with HIV, and they do not feel like that at all. Everything is fine. They don’t need anything. They wouldn’t separate themselves from the rest of the people as ill people.”*

**Needs in knowledge about HIV and TB.** Lack of knowledge about HIV and PLTB is the result of the lack of a visual aids system, charts and algorithm scheme of decision making in different scenarios, – something like ‘10 steps’ algorithm.

**Need in PLWH communities.** The PLWH still believe that they need support in the form of clubs for PLWH, which have already started to be created by NGOs and TPs, since the latter ‘care more about us’.

**Rehabilitation and involvement into people’s (not PLWH) communities.** The PLWH think that the most important component of psychological support would be jobs in common spheres of occupation. For that, they need consultation and support on the part of lawyers who could help them find a job, obtain professions in which the HIV status wouldn’t be an obstacle, and for PLWH with children – get benefits in getting children in kindergartens.

*“I know that I’ve only got a few years to live, but this doesn’t mean that I should kill myself. You shouldn’t just exist waiting for the end, you should live a life.” FGD-PLWH+PWID-F-30*

Need in the knowledge about the rights.

*FGD-PLWH-M-TBt-44 and FGD-PLWH-M-TBt-52 “We should get what we have the right for. I am coming to take my pills, but I don’t know what I am entitled to. I’d like to at least know about that.”*

*FGD-PLWH-M-TBt-44 “I learned about some of my rights from outreach workers only.”*

**Legal protection in gender relations.** Some SWs with HIV need lawyers' or NGOs' help to protect them from their cohabitants. These cohabitants or pimps are blackmailing them threatening to tell everybody about their HIV status and beating them for the same status and their risks of getting infected, forcing them to go on the streets to earn money.

PLWH should have the right to choose a health facility according to the quality of its services. The PLWH state that their opinion is not taken into consideration when making a decision about the place of treatment. Some PLWH prefer outpatient treatment at the Virology Institute rather than at their district polyclinic, while the other, – on the contrary, – would like to get treatment at their polyclinic or at an AIDS Center.

The PLWH mentioned cases when some health facilities do not have needed pharmaceuticals, and the PLWH would either buy them and bring them to a health facility or cannot buy them and get treatment for their diseases (not HIV/AIDS).

*“We ourselves are bringing medicines and buying antibiotics. We are only asking them to make injections.” FGD-PLWH+PWID-M-32*

**Reduction of the number of NGOs.** Some PLWH believe that the government is cutting down the number NGOs intentionally, – so that PLWH would die sooner.

*“Someone somewhere created a program for those like us - to simply get rid of us.” PWID-PLWH-M-38*

The PLWH have good memories of the activities of 'Contact' NGO that had been closed, and are hoping for a resuming of their activities.

*“When we attended 'Contact' we received assistance there. They organized different activities for us. Why did they close it?” FGD-PLWH+PWID-F-32*

## **PLWH+TB KNOWLEDGE, ATTITUDES AND PRACTICES**

### **Knowledge, Attitudes and Practices towards TB**

#### **Composite profile of PLWH with TB**

- Age: 20-46;
- Gender: male and female;
- Married to PWID or PLTB, or single/divorced/widowed;
- Have children, including PLWH;
- Have been, or are, PWID and SWs;
- Acquired the PLTB status as a result of AIDS, or were infected by family members;
- After acquiring the status of PLWH with TB, lost the status of well-off people and the social status;
- Disabled, unemployed, or have occasional and low-paid occupation;

This Section of the Report focuses on the peculiarities of the knowledge, attitudes and practices of PLWH with TB, without repetition of the results of FGDs with SWs, PWID and PLWH prior to their PLTB status, – not to say the same as has already been mentioned in the previous sections where PLWH with TB had the same knowledge, attitudes and practices.

**Knowledge on TB.** In 2012, as well as in 2011, the PLWH with TB had detailed knowledge about TB, and mentioned the sources of knowledge, symptoms, modes of transmission and methods of protection of other people against TB.

*“Persistent fever for two weeks and more, cough, weakness, perspiration and night sweats, labored respiration, then blood spitting or productive cough, sputum of specific color.” M-PLWH+TB+PWID*

However, all this knowledge was post-factum, while the disease initially was growing worse due to the same lack of knowledge as in PWID and SWs, which resulted in self-treatment of symptoms believed to be the symptoms of a cold, without timely TB diagnostics.

*PLWH+TB-F-43 “I couldn’t understand for a long time why I felt so sick. I knew that I had HIV, but I had never felt that sick before. First I had a fever and pneumonia. I called in a doctor, and she said it was bronchitis. I started to treat bronchitis, and it looked like it helped. However, later I felt worse, again, - I couldn’t even walk. I lost appetite. I had to call my mother. She was taking me to different doctors. First, I had an ultrasound examination of the kidneys, which didn’t show any problems. Then I did a cardiogram, and my heart looked OK. One doctor advised me to do an X-ray, and they found water accumulated in my lungs and foci of TB.”*

*“My husband was ill, and he told me that if you are over 30 years old you are not likely to catch tuberculosis, - like, you shouldn’t worry. But then it turned out...” F-PLWH+TB+PWID*

*PLWH+TB-F-25 “I don’t know why I got ill with tuberculosis, and before that I didn’t know what tuberculosis was like. I was hospitalized with pleuritis. When they had withdrawn fluid they could see TB foci in both lungs.”*

*PLWH+TB-M-46 “I couldn’t understand the reason for my fever and weakness for a long time. I thought I had a cold hoping it would go away. I was taking paracetamol to bring down the temperature, and it would help for some time, but then I would have it again. Then I started coughing and losing weight. I had to go for a fluorography test. Then they advised me to do a high resolution X-ray, and they saw a focus there.”*

*PLWH+TB-F-40 “I had a fever in the beginning, - when я caught a cold, - however, my mother was giving me injections for colds, and now it seems like I have normal temperature. Only stuffed nose and cough (the respondent was frequently and continuously coughing during the interview).*

**Sources of knowledge.** In 2012, the PLWH with TB emphasized the activities of outreach workers, TPs and their doctors who provided them with access and knowledge about TB, with diagnostics and psychological support.

*PLWH+TB-M-46 “Outreach workers were telling us about TB at the Anonymous Consulting Room. They said that if you’ve been diagnosed with TB but are following all the doctor’s prescriptions, and taking pills, you’ll be able to recover. You shouldn’t think that if you got sick you are going to die, etc.”*

*PLWH+TB-F-40 “There’s a lot of information about this these days. There are even brochures about tuberculosis at Trust Points. I’ve got many of these brochures at home – both about HIV and about tuberculosis.”*

*PLWH+TB-M-46 “There’s a project named ‘Intilish’. We are going there to meet with each other. They are working with us there both on HIV and tuberculosis, giving brochures, organizing round tables.”*



*PLWH+TB-M-46 “I’ve been often getting consultation - either at TPs, or outreach workers themselves are coming to see me at home once a week.”*

*PLWH+TB-F-43 “When I found out what kind of disease that is I started to learn about it. I bought special literature and started to ask doctors about it. And when I got hospitalized I learned about the DOTS program treatment. If you follow all the requirements of this treatment you’ll be able to cure yourself.”*

**Types and quality of services.** If in 2011 the PLWH with TB had difficulties in diagnostics and access to treatment, in 2012 they stated that the accessibility of diagnostics and free treatment had significantly improved, which is also due to the activities of outreach workers, TPs and the AIDS Center.

*PLWH+TB-F-43 “Outreach workers helped me do an X-ray, gave me useful literature to read, conducted seminars in HIV/AIDS, tuberculosis and hepatitis.”*

*PLWH+TB-F-40 “Valera (an outreach worker) told me that I could come to the ACR for fluorography and blood tests.”*

*PLWH+TB-M-46 “I was sure that nothing could be free. But then outreach workers explained it to me, and they were right: when I got hospitalized everything was free - both and injections.”*

*PLWH+TB-F-43 “It was fast. First I did an X-ray; the rontgenologist referred me to an infectiologist who gave me a referral to the tuberculosis dispensary. I came there, and the rontgenologist looked at the X-ray and submitted all the data to our district doctor, and she gave me a referral to the tuberculosis hospital, and the next day I was hospitalized. It took me only 3-4 days.”*

Both in 2011 and in 2012, some of the PLWH with TB mentioned lack of coordination between health facilities in prisons and public health facilities at the place of residence of returned former prisoners, – for example, a case with a person with HIV and TB who was released from a prison, but due to the lack of prompt communication between these facilities could not get a course of DOTS treatment.

*“They (polyclinic health personnel) didn’t even know that he came back from a prison with TB.” PLWH+TB+PWID*

*PLWH+TB-F-49 “Sasha cannot get treatment for his tuberculosis. After he had been released he was taken to the tuberculosis institute, and they were supposed to deliver DOTS medicines for him. However, they did not do that, and he cannot get medicines for DOTS. He just gave up and hasn’t been treating his tuberculosis for a whole year already.”*

As in the other FGDs with MARPs, the PLWH with TB mentioned that confidentiality in case of diagnosing TB is frequently violated, however, it is not violated by TPs.”

*PLWH+TB-M-39 “I did an X-ray in December, having applied a code only. No name or passport was needed.”*

*PLWH+TB-F-43 “If they diagnose HIV nobody is being informed. While if you are diagnosed with tuberculosis there’s no anonymity. They ask you for your passport, then inform your polyclinic, who informs your mahalla, and so on and so forth.”*

The PLWH with TB, in spite of confidentiality violation, mentioned the improving the quality of doctors’ services, – more friendliness on their part, more accurate performance of their obligations, including informing PLTB about the necessity of adherence to treatment course.

*“Before, doctors at polyclinics replied in a rude manner to me if I asked any question.” F-PLWH+TB+PWID*

*PLWH+TB-F-25 “Now they treat us decently. My doctor at the polyclinic - a TB specialist, Dilya, - is nice, we are like friends with her.”*

*PLWH+TB-F-25 “I stayed at the TBPC for 2 months, but my doctor made me stay for one more month, - he said that I had progressive HIV and tuberculosis. He said: ‘I’m going to give you more treatment, you should stay for another month’. A month later my tuberculosis was better, and then I was hospitalized at the Virology Institute to get treatment for HIV.”*

*PLWH+TB-F-43 “One should do everything in due time. And do everything they prescribe to you. In this case you’ll be able to cure yourself. But if you discontinue your treatment it will be useless.”*

*PLWH+TB-F-43 “With HIV, one can last for some time, but tuberculosis has to be treated immediately. Especially if it’s smear-positive you can infect other people.”*

**Social support for PLWH with TB.** If in 2011, the PLWH with TB stated that they needed psychological, financial and medical assistance, in 2012 they only mentioned financial support, including during treatment.

*“I don’t have a job. I haven’t seen anything free, except DOTS. Food in hospitals is poor, you have to buy fats, milk products. You simply don’t have money to get to the hospital.” M-PLWH+TB+PWID*

Like in 2011, few of the PLWH with TB mentioned that they had received social support in the form of food packages under the DOTS programs or allowances in communities/mahallas.

*PLWH+TB-F-43 “They gave me food packages under the DOTS program at the TBPC. It was a great help for me. At this time neither I nor my husband were working. After I brought a paper to my mahalla from my polyclinic infectiologist I was receiving allowance for six months.”*

*“I don’t even know where to turn to. When I was at the hospital I was told that I could receive some food once in four months. They said that somebody would come to me or call me and tell me where I should come to get these food packages. However, I never received any calls. I came to my mahalla committee to get my children’s allowance, but they came to my home, and when they saw my little dog they said: ‘You’ve got enough money for your dog but don’t have it for your child?!’, and refused me the allowance.” F-PLWH+TB+PWID*

*“I hear it for the first time that doctors at the TBPC should tell you that you are entitled to food packages and financial assistance from your mahalla.” M-PLWH+TB*

The PLWH with TB suggest that the PLWH with TB who need social allowances and social assistance should be registered with mahallas, or TBPC should inform mahallas about them.

*FGD-PLWH-M-TBt-52 “Mahallas and khokimiyats should have data on their TB patients, so that social workers would come to them at least sometimes, bring a bottle of oil, a kilo of macaroni.”*

*FGD-PLWH-M-TBt-53 “They should receive some support, - with food or money for medicines, - depending on what they need more. If they need food they should be given food, if they need money - money, if medicines, let them bring them medicines.”*

Like in 2011, the PLWH state that due to their low incomes, lack of social assistance and no possibility to leave children unattended they have to rely to self-treatment, and are seeking treatment for their TB when it is already too late, which results in advanced forms of TB.

*“I am getting colds now and then, taking Isoniazid, then I would have a fever, and I can feel that the process is starting, again. Especially in the fall and spring. I am actually not getting any treatment now. It’s very expensive. Too costly. I’ve got no job.” M-PLWH+TB+IDU*

As before, some of the PLWH with TB mentioned that nobody forced them to get treatment for TB. Other mentioned cases of prompt interaction between health facilities (except prison health facilities) in control over treatment or termination of treatment. Lack of control over taking DOTS medications, which resulted in termination of treatment or its inefficiency were also mentioned.

### **Knowledge, Attitudes and Practices towards HIV**

**Knowledge on HIV.** The PLWH with TB, – like in the case with PLWH, – had good knowledge of HIV/AIDS, its etiology, modes of transmission, treatment, prevention, etc. When discussing the issues related to HIV participants of this group mentioned special terms (like ELISA, immunoblot, etc.) which was the sign of their in depth knowledge.

**Sources of building knowledge and attitudes.** Both in 2011 and in 2012, the main sources of knowledge and support were the employees of the AIDS Center, Virology Institute, TPs, outreach workers, NGOs, as well as people living with HIV and TB themselves who were sharing their knowledge with each other and when meeting at TPs.

*PLWH+TB-F-25 “The AIDS Center organized meetings where social workers (outreach workers) were inviting us. There were doctors there who were explaining everything to us in simple language, showing pictures with an overhead projector on the screen. For example, at the AIDS Center in December, 2011.”*

*PLWH+TB-M-46 “There is a project ‘Intilish’. They are working both on HIV and tuberculosis. They are giving away brochures, and also memorandums on HIV. They conducted round tables. We all met there.”*

*PLWH+TB-F-40 “A psychologist was working with us there. All the addicts were coming there. They organized tea parties for us. Tatyana took us to the theatre and to the movies, - they gave us free tickets.”*

In 2012, the female PLWH with TB mentioned cases when doctors supported women who was seeking knowledge and willing to have children.

*PLWH+TB-F-25 “I asked a doctor at the Virology Institute, and he said that you can have children, however, take care of your health and give birth via Cesarean section, and should not breastfeed your baby. We were told this during our training seminars, too.”*

In 2011, the PLWH with TB frequently mentioned such a source of knowledge as Internet, which helped them communicate with PLWH abroad, as well as with different international non-governmental organizations. B 2012, the PLWH with TB did not mention such sources of knowledge, and could not name any international NGOs that are providing assistance to PLWH with TB.

**VCT.** In 2011, the PLWH with TB mentioned cases of occasional sporadic efforts to get VCT services.

*“I was sick for a long time, and I did tests at my polyclinic for all possible infections, but it didn’t show anything, and they couldn’t tell anything. My neighbor, - a doctor, - advised me to go to for an HIV test at the AIDS Center. I did an anonymous test at the Republican AIDS Center, and three tests at the Anonymous Consulting Room. The last test took a long time, - they were probably double-checking it.” M-PLWH+TB+PWID*

In 2012, the PLWH with TB were describing all cases of getting VCT as a system of receiving services via outreach workers who were advising them to apply to an ACR and AIDS Center, and/or taking them there themselves.

Some of the PLWH with TB still did not know the term ‘voluntary testing and consultation for HIV’, however, their statements about the experience of getting VCT proves that VCT is accessible and is being widely practiced by the PLWH with TB.

The reaction of the PLWH themselves, their relatives and acquaintances to the results of such testing was panic. However, the experience of getting VCT resulted in a reduction of fear of VCT.

*They have a psychologist there now on staff, because there were a lot of cases when addicts died of overdose after having learned that they were HIV infected.” M-PLWH+TB+PWID(2011)*

**Accessibility, quality and types of services.** The accessibility, quality and types of services for the PLWH with TB have significantly improved. If the accessibility of services for PLWH and their relatives is limited it is only in some cases when people are not aware of facilities and outreach workers who can provide these services.

*F-PLWH+TB-43 “A friend of mine has a brother who was diagnosed with HIV. She called me and asked me about the ways of transmission and how you can protect yourself. They don’t know anything about this disease that is why they are scared. I advised her brother to go to the AIDS Center.”*

The PLWH with TB continue to mention assistance on the part of ACR and AIDS Center personnel in maintaining the health of the PLWH with TB, emphasizing services provided by outreach workers in psychological support.

*“ AIDS Center workers would tell you that you should get treatment, and improve your immunity if you want to live longer.” F-PLWH+TB+PWID*

*PLWH+TB-M-46 “The outreach workers of the Anonymous Consulting Room said that if you follow your doctor’s administrations strictly, and take pills, you will be able to cure yourself. You shouldn’t think that if you get ill you are to die.”*

In 2012, the coverage of PLWH with TB by TPs has been widened by the coverage of the PLWH with TB by their local health facilities.

*PLWH+TB-M-46 “I’ve been coming to TPs regularly, and outreach workers are coming to see me at home once a week.”*

The PLWH with TB still state that they have access to syringes and condoms, however, this accessibility is not stable.

*“Volunteers would bring free syringes and condoms as soon as you call them.” M-PLWH+TB+PWID*

*PLWH+TB-M-45 “They now have more of them at TPs, but sometime ago they wouldn’t give you anything, - about year and a half ago. At that time we were having problems with syringes and condoms.”*

*PLWH+TB-F-40 “They would often tell you that they don’t have 2- or 5-gram syringes.”*

In 2011, the PLWH with TB mentioned cases of stigmatization of PLWH by doctors.

*“One doctor was yelling at the City Cancer Hospital: ‘HIV infected are all addicts!’.” M-PLWH+TB+PWID*

In 2012, the quality of doctors' services has improved because some doctors have been trained at courses and seminars on HIV, and those doctors who were providing inadequate services to PLWH are now being punished. Doctors who still discriminate PLWH with TB can only be met in provinces. The PLWH with TB believe that nurses should also undergo the same kind of training, since they deal with patients even more frequently than doctors.

*PLWH+TB-F-25 "Social workers were organizing training seminars and were inviting health personnel from polyclinics. They explained them that they shouldn't be afraid of us, and that we are like all the other people. And these doctors were telling their polyclinic employees about this afterwards. However, there are still some who would try to avoid even touching you, putting on gloves and masks in a pointed manner, but this mostly happens outside Tashkent. There are such doctors in Yangiyul."*

*F-PLWH+TB-43 "Doctors' attitude towards people like me has changed. They are more polite now. Probably because they are afraid that someone might sue them. Or, they must have realized what HIV is and that nobody is secured against it, therefore they are treating us with more understanding now."* F-PLWH+TB-43, doctor

*F-PLWH+TB-43 "If they find out at the polyclinic about HIV they would immediately inform the mahalla. And if mahalla employees learn about it this means everybody will know that. It happened once that I had to go to the polyclinic but I couldn't, and a nurse went to the district police officer, and he came and started telling all my neighbors that I should come to the polyclinic. I came to this nurse and told her: 'Am I a criminal that a police officer needs to take me to the polyclinic?!'. I was going to complain about her to the Head Physician, but she started crying and asked me not to do that."*

If in 2011, the PLWH with TB who were taking IDs had a very negative opinion of the services they had received at the narcological dispensary (ND), in 2012, – as a result of outreach workers' support, – the quality of services at the ND has been improved, in their opinion.

*PLWH+TB-F-40 "If you need, Valera would help with Narcologiya (the ND) - would pick up a referral and would take you there himself. And would even visit you there. Valera is a reliable person, he would always do what he promises."*

**Knowledge and practice of protecting other people.** The PLWH with TB mention cases when they got TB from their family members, – specifically, from spouses. It was mostly women – the PLWH with TB – who stated that.

Having had this kind of experience and knowledge about modes of TB transmission, the PLWH with TB are now taking measures not to infect other people.

*"I myself would never give my plate or cigarette to anybody because I know (that I can infect them)." M-PLWH+TB+PWID*

Like in 2011, the PLWH with TB, looking for income, are providing their acquaintances and neighbors unofficial medical services, or are working in the service sector where they might have contact with their clients' blood.

**Accessibility and quality of treatment.** Like in the FGDs with PLWH, the PLWH with TB still state that treatment and preparations are free at the Virology Institute, with the exception of syringes, blood transfusion systems, and medical preparations for associated illnesses.

In 2012, the PLWH with TB continued to mention the low quality of services at the Virology Institute, the need to bring food to the hospital, or buy it somewhere outside the hospital, remembering good conditions at this Institute after it had been opened, when meals were very good there.

*PLWH+TB-M-41 "I stayed there in 2006. They would give us pieces of meat, butter, sugar! Food was healthy in those times - cheese and curd cakes. They had everything: IV lines, medicines! But if you are going to be hospitalized you have to buy IV lines and antibiotics yourself, and sometimes they don't even have syringes. We are so glad that there is an ACR at Children's Hospital #5 nearby, where we can get syringes. To make it short, you have to bring money there to get treatment. They can only administer treatment for you, but do not have anything."*

In 2011, some of the PLWH with TB stated that the lack of pharmaceuticals at the Virology Institute was hidden by the imitation of their availability and patients were being threatened with non-provision of treatment in case they reveal the truth. In 2012, there were no such statements.

**Practices of receiving treatment services.** The PLWH with TB still state that, in spite of the practice of combining the ART and DOTS courses, the PLWH with TB prefer separate treatment, when an ART course is terminated for a DOTS course, and only after that the ART course is continued. The reasons for that is the fact that the PLWH with TB find it hard to consume so many pharmaceuticals at the same time, and are mentioning cases when people were dying of this combined treatment.

*"They wouldn't start treating HIV (ART course) before they have cured tuberculosis." M-PLWH+TB+PWID*

*"They told me that after I've finished all my pills for tuberculosis I could come to the Virology Institute." M-PLWH+TB+PWID*

*"These drugs are affecting your mental state. I saw once a guy who, all of a sudden, smashed all the mirrors in the bathroom, and started cutting his veins." M-PLWH+TB+PWID*

*"I was immediately administered DOTS preparations, vitamins, Isoniazid for my immune system. First, I was also taking vitamins B6, then a drip with glucose." M-PLWH+TB+PWID*

*First you have to get a treatment course at a hospital (TBPC). Then, supporting ART treatment for 9 months, take preparations regularly, however, these preparations have some effect on your body." M-PLWH+TB+PWID*

Some PLWH stated that doctors at the TBPC and AIDS Center were taking into consideration the peculiarities of patients' reactions to different pharmaceuticals, and were replacing them if necessary.

*"I had to take both ART and DOTS preparations which made me so sick that they called the AIDS Center, and decided to change preparations for my treatment of TB. Then they picked up preparations for treatment of TB so that they agreed with ART." M-PLWH+TB+PWID*

### **Knowledge, Attitudes and Practices towards IDs**

The PLWH with TB are aware of the laws and regulations aimed to reduce the drug use, and are very positive about those.

*PLWH+TB-M-44 "Heroin has disappeared, at all. For some time, Codacet was very popular. Now even this stuff is strictly forbidden. Maybe it's inhuman to treat drug addicts this way, but it's the only way to stop the inflow of drugs."*

Some of the PLWH with TB would explain these regulation measures by competition in the drug market and a desire to monopolize it.

*PLWH+TB-M-44 "Why have the heroin price raised? If before it was 100 people who were bringing it here, now it's only one. He is being supported by corrupted officials in the security structures. Everybody knows that. I think I haven't said anything that you didn't know."*

*PLWH+TB-F-40 'One could easily find it before. Even teens could buy it. But these days, I wouldn't hear in our district, - where there are many 'barygas' (pushers) selling the stuff, - that you could buy it. It's not to anyone that they would sell it, and as little as one gram only.'*

Only in the group of the PLWH with TB, they mentioned how a PWID could be helped in case of an overdose.

*PLWH+TB-F-40 "Many PWID don't know what they should do in case of an overdose. However, we do know that if someone gets himself zunked somebody should inject saline solution into his vein to dilute the drug. Of course, clean saline solution."*

The PLWH with TB confirmed the results of the other FGDs that sharing syringes or needles when taking IDs has become rare.

*PLWH+TB-M-45 "It's not the case anymore, it's all in the past. Each PWID in a group has his own syringe these days. Everybody knows about the HIV risk."*

*PLWH+TB-M-39. "If somebody is HIV infected they would put the stuff for him in a separate cup/spoon, and he himself prepares it, or healthy guys would jab first, and only then the PLWH, because they already don't have anything to worry about. That is why I would first give it to my wife, because she's healthy."*

Like in the other groups, the PLWH with TB state that the efficiency of drug addiction treatment mostly depends on the ability of an PWID or his relatives to pay.

*PLWH+TB-F-40 "I would yen for drugs or for alcohol now and then. My mother would take me not to the hospital but to the doctor's. For money, of course."*

The PLWH with TB mentioned some other methods of injecting heroin, – not mentioned in the other MARPs, – such as subcutaneous.

*"One should know how to prepare Dope or Codacet. As for heroin, you can smoke it, snort, jab, or even eat. If you scratch your skin and sprinkle with heroin, and then put an adhesive plaster on top, the effect will be the same."*

### **Knowledge, Attitudes and Practices towards STDs**

Among different sources of detailed knowledge on STDs, the PLWH with TB emphasized such sources outreach workers, and ACR and AIDS Center employees.

*PLWH+TB-F-39 "Julia and Jakhangir told us, girls, about it at our meetings. How would I know that my husband steps out on me? That is why I listened carefully what are the signs, how one should treat the infection, how to protect yourself. One girl said she had kind of spots with blisters inside. Jakhangir asked if they would break, and if there is pus there. And he said that that she had genital herpes, and it should be treated as soon as possible. He suggested that they should go together to the KVD for consultation and treatment administration. Jakhangir said that it would be anonymous, and nobody would force her to go to the hospital. After that she agreed to go with him. She was administered treatment there, and she was taking all the pills at home."*

There were no obstacles in obtaining knowledge on STDs for the PLWH with TB, however, the PLWH with TB mentioned that there were not enough booklets and brochures.

*"There was a resolution that booklets and brochures should be approved by specialists prior to being printed. It's hard to get this approval. That is why there are not so many booklets now. However, they would be very useful for teens." M-PLWH+TB+PWID*

As before, the PLWH with TB mentioned cases of risks of ignoring PPDs by those with the status of PLWH, as well as cases when some SWs (PLWH) would intentionally conceal their PLWH status when providing services to their clients.

*PLWH+TB-F-32 “I asked her: ‘How could you go and infect a person?!’. And she says: ‘He’s old, he’s going to die soon, anyway.’ She used to have a lot of partners whom she didn’t inform about her HIV status. Maybe she’s afraid of it, however, some people would say: ‘Why is it only me who has to be ill?!’”*

### **Needs and Recommendations of PLWH with TB**

Below is the list of needs and recommendations of the PLWH with TB.

#### **Delivering pharmaceuticals and food packages to places of residence of the PLWH with TB**

*PLWH+TB-M-46 “I felt so sick that I couldn’t go and pick up the pills. I was so weak that I could hardly get up from my bed to go to the bathroom.”*

*F-PLWH+TB-43 “I don’t know. It’s so hard to go there to get my pills. It’s easier to get to the Republican AIDS Center, but the City Center is too far.”*

*PLWH+TB-M-45 “Sometimes I’ve got a fever, and cannot even get out of my bed for two-three days, and I don’t even have money for bread. And there’s nobody I could call.”*

*FGD-PLWH-M-TBt-52 “Khokimiyats should have data on their TB patients. They would be happy to see a social worker coming to visit them at least sometimes, bringing a bottle of oil and a kilogram of macaroni.”*

*FGD-PLWH-M-TBt-37 “They are almost no such things these days.”*

#### **Need in access to ART and special medications**

*F-PLWH+TB-43 “My CD was normal, somehow. They once administered treatment to me, but it turned out that there were no pills available.”*

*PLWH+TB-M-44 “I am not taking any treatment, because I don’t have any medicines. Simple preparations are useless, - they will only make me feel worse, - but I can’t afford special preparations.”*

#### **Need in NGOs**

*PLWH+TB-F-40 “I am now associating with Valera only. Before, I used to go to ‘Contact’. They were doing a good job, and many of us used to come there. They were giving us food packages, and even money for a bus. Now, there are almost no such organizations left.”*

#### **Need of changing the order of access to syringe exchange**

*PLWH+TB-F-40 “If you come for the first time they will give you syringes for free. But after that you’ll have to bring these used syringes back to get new ones. Who would be walking around with used syringes? What if a police officer stops you and finds a used syringe? They tell you at the Trust Point that syringes should have blood on them.”*

**Involve family members and neighbors of PLWH and TB in information campaigns** to develop tolerant attitude towards them.

*PLWH+TB-F-25 “They should disseminate more information among the population. First of all, among relatives so that they knew everything and were not afraid. They should be asked to come to TPs to participate in meetings.”*

**Insufficient representativeness of PLWH with TB in information campaigns** and willingness of the PLWH with TB to participate in such campaigns.



*PLWH+TB-M-41 "If I could I would make a film about PLWH with TB, and would invite people to watch it anonymously."*

*PLWH+TB-M-39 "This is necessary for those who just found out that they are HIV infected, because it's a shock for them, and some commit suicide. For example, 3 years ago I explained to one such guy diagnosed with HIV that I had been living with HIV for several years already. I talked him out of a suicide, - I said that he could live 8-12 years, and even more if he takes ART."*

**Need to correct the situation with the accessibility of ART course depending on domicile registration**

*PLWH+TB-M-39 "I was taking ART at my polyclinic according to my 'domicile registration' in 2009-2010. Then they submitted an inquiry to the Passport Office and found out that I had only a temporary registration, and the AIDS Center stopped supplying ART preparations for me. Now I have to go as far as to the City AIDS Center."*

**Pay attention to prisons as high TB risks institutions, and improve the efficiency of prevention measures for TB there.**

*PLWH+TB-M-44 "In prisons, PLWH have a high risk to get infected with tuberculosis. There are no conditions there to protect yourself against TB. Very poor nutrition. There are 150-180 people in a barrack, sleeping on 3-tiered bunks. Double beds. Very damp. No ventilation in the summer and poor heating in the winter. Everything is in a cell - a toilet, a sink, and they eat there, too."*

**Need to improve the quality of services at the AIDS Center**

*PLWH+TB-F-46 "I came to the AIDS Center on Tuesday, - we had a meeting with outreach workers. I wanted to consult with a gynecologist. But they told me: 'We don't have a gynecologist today!' (in an imperious tone). They suggested that I see a male doctor for examination. He just looked at me at a distance (showing a distance with her arms), wouldn't even put on his gloves or instruments, or a speculum, or something else. Looked at me at a distance and said that everything was OK."*

*"Before, we could even see a dentist there, but now all the rooms are closed. Only one physician and one psychologist!"*

**Need to take care of children for women - PLWH with TB, who do not have anybody to look after their children during their hospitalization.**

*"My doctor told me to start ART. She said that with my tuberculosis, I'm going to feel worse and worse. I told him that I wouldn't do it. He gave me a referral immediately to the Virology Institute. She said that I should get this treatment, by all means. I said OK, but I never went there because I don't have anybody to look after my children." 8-F-PLWH+TB*

**Need in social housing.** The PLWH with TB need separate rooms or a possibility to live separately from their unaffected family members (in order not to put at risk their health), however, they should be able to visit them in case of necessity.

*"I need a separate room. Now my daughter lives at my brother's. But if I didn't have a brother, or had several kids, she would have to live with me. I'd rather live alone and be a 'weekend mother'. F-PLWH+TB+PWID*

## ATTACHMENTS

### TECHNICAL REPORT

#### Methodology

The goal of the survey is to obtain information on the knowledge, attitudes and practices towards TB and HIV among the target groups, and to define their behavior towards TB and HIV.

1. For the implementation of the Project, there was created a working group:

Name	Position	Obligations
Arustan Joldasov	Manager/Analyst	Design/adaptation of field instruments, drafting of an Analytical Report.
Mavlyuda Eshtuhtarova	FGD Moderator and Interviewer	Organization of FGDs and IDIs, works management and control over their quality, moderation of FGDs and interviews
Alexsandr Trotsenko, Elena Smirnova, Djahangir Umarov, Svetlana Eremenko, Viktor Kim, Valeriy Chekmenev	HOPE Outreach Workers	Recruiting of FGD and IDI participants
Khasan Nazarov	Moderator and Interviewer	Moderation of interviews
Irina Suraeva, Margarita Yavna, Mira Dauletbaeva, Anton Tujilin, Alisher Kholmatov	Stenographers and translators of FGDs and interviews	Transcription/translation of FGDs and interviews

In total, there were conducted 12 FGDs and 10 IDIs during the survey. The number of FGD participants was 7-10 per FGD.

#### Sampling

Table. Structure and number of FGD and IDIs

1. FGD	
Topic 1. Knowledge, Attitude and Behavioral Practices in the Issues of HIV/AIDS	
PWID	1 FGD with men and 1 FGD with women
SWs	1 FGD with men and 1 FGD with women
PLWH	1 FGD with men and 1 FGD with women
PLWH	1 FGD with men and 1 FGD with women
Topic 2. Knowledge, Attitude and Behavioral Practices in the Issues of TB	
PWID	1 FGD with men and 1 FGD with women
SWs	1 FGD with men and 1 FGD with women

PLWH	1 FGD with men and 1 FGD with women	
PLWH	1 FGD with men and 1 FGD with women	
2. In-depth interviews		
PLWH with TB	5 men	5 women

## Training

Training for moderators was held on June 25, 2012 in Tashkent c. with Dialogue Project and the Republican AIDS Center specialists.

Training schedule:

- 1) Introduction. Explanation of the contents of the survey, its tasks and methods;
- 2) Discussion of questions with Guides.

## Field Works

2. The fieldworks started on June 19, 2011, and included recruiting participants and conducting FGDs and IDIs. The fieldworks were completed on June 6, 2012.

Table. Schedule of conducting the survey.

<b>Works</b>	<b>Started</b>	<b>Finished</b>
Recruiting of FGD and IDIs participants	June 19	July 6
Development, translation and approval of Guides	June 15	June 22
Conducting FGD	June 25	July 4
Conducting IDIs	July 2	July 6
Transcription of FGD and IDIs	June 27	July 26
Technical Report	July 26	July 29
Analytical Report	July 26	August 10

The Table below shows the dates on which the FGDs and IDIs were conducted, by their types.

Table. Schedule of FGDs and IDIs by their types.

FGD/IDI #	FGD/IDI	Specification	Main Topic of FGD/IDIs	Date	Location
1	FGD	PWID (women)	HIV	25. 06.2012	<i>Expert-fikri</i> office
2		PWID (men)	HIV	25. 06.2012	<i>Expert-fikri</i> office
3	FGD	PWID (men)	TB	26. 06.2012	<i>Expert-fikri</i> office
4		PWID (women)	TB	26. 06.2012	<i>Expert-fikri</i> office
5	FGD	SWs	TB	27. 06.2012	<i>Expert-fikri</i> office
6		SWs	HIV	27. 06.2012	<i>Expert-fikri</i> office
7	FGD	SWs	TB	04. 07.2012	<i>Expert-fikri</i> office
8		SWs	HIV	28. 06.2012	<i>Expert-fikri</i> office
9	FGD	PLWH (men)	TB	29. 06.2012	<i>Expert-fikri</i> office
10		PLWH (women)	TB	29. 06.2012	<i>Expert-fikri</i> office
11	FGD	PLWH (men)	HIV	06. 07.2012	<i>Expert-fikri</i> office
12	FGD	PLWH (women)	HIV	06. 07.2012	<i>Expert-fikri</i> office
1	IDIs	PLWH+TB	HIV+TB+STD	02. 07.2012	Trust Point at family polyclinic №33
2		PLWH+TB	HIV+TB+STD	03. 07.2012	<i>Expert-fikri</i> office
3		PLWH+TB	HIV+TB+STD	04. 07.2012	<i>Expert-fikri</i> office
4		PLWH+TB	HIV+TB+STD	06. 07.2012	<i>Expert-fikri</i> office
5		PLWH+TB	HIV+TB+STD	06. 07.2012	<i>Expert-fikri</i> office
6		PLWH+TB	HIV+TB+STD	02. 07.2012	Trust Point at family polyclinic №33
7		PLWH+TB	HIV+TB+STD	02. 07.2012	Trust Point at family polyclinic №33
8		PLWH+TB	HIV+TB+STD	03. 07.2012	<i>Expert-fikri</i> office
9		PLWH+TB	HIV+TB+STD	06. 07.2012	<i>Expert-fikri</i> office
10		PLWH+TB	HIV+TB+STD	06. 07.2012	<i>Expert-fikri</i> office

VG representatives were recruited by outreach workers. These representatives were of those who had had experience of being impacted by NGOs, health facilities, as well as of those who had not had such experience. The share of MARPs representatives who had participated in the 2011 survey was about 9% of those who participated in the 2012 survey.

The total number of FGD and IDI participants was 102 representatives of target MARPs.

The table below shows the distribution by the number of participants, by types.

<b>Type of VG</b>	<b>Number of FGDs/IDIs participants</b>
PWID (men)	15
PWID (women)	17
SWs	30
PLWH (men)	16
PLWH (women)	14
PLWH+TB – men	5
PLWH+TB – women	5
<b>TOTAL</b>	<b>102</b>

### **Peculiarities of field works**

10. Representatives of target groups were selected by outreach workers with the help of screener questionnaires which had questions for that helped determine whether the respondent met the goals of the survey. For identification of respondents, each of them was assigned a unique code consisting of the first two letters of their mother's and father's names, the last numbers of their year of birth, and the gender code. This looked like a guarantee of confidentiality for the respondents, and was one of the incentives for participation in the survey.

11. Prior to each FGD and IDI, respondents were to sign a Consent Letter confirming their voluntary participation in the survey.

VG representatives were informed that they were participating in the survey on a voluntary basis, and that even after the start of the discussion they can cancel their participation in the survey.

The FGD and IDIs were conducted in an atmosphere comfortable for all the participants, which helped the participants to be open.

12. The incentive for the participation in the survey was financial assistance and reimbursement of transportation expenses for coming to the *Expert-fikri* office and for the taxi to take them home. One of the important factors of willingness to participate in the survey was close relationships between outreach workers and respondents. All the respondents had known the outreach workers personally for half a year or more, and trusted them.

The proof of participants' confidence in moderators during FGDs and IDIs was the fact that nobody of the participants was against the use of the dictating machine, – they had all been informed about it in the beginning of discussions, and permission received from all of them.

Difficulties faced during the FGDs and IDIs were related to the respondents' physical condition – in some cases respondents were under the influence of drugs, or were not feeling well due to HIV and/or tuberculosis.

Because of a failure to conduct one FGD with SWs at a scheduled time, the schedule of FGDs and IDIs was shifted by 2 days (until July 6 instead of the planned July 4).

Changing weather and atmospheric pressure during the survey was the reason for shortening the duration of some IDIs at the request of the respondents who were feeling especially sick on these days.

All the FGDs were conducted in *Ekspert-fikri* office in a special room with a mirror wall.

The IDI participants were themselves choosing places for interviews with them. Three IDIs were conducted in the Trust Point at Family Polyclinic № 33, the rest 7 IDIs – in *Ekspert-fikri* office.

Taking into consideration the flaws in recruiting participants for FGDs and IDIs in 2011 by some employees of the City and Republican AIDS Centers, in 2012 recruiting was done only with the help of outreach workers. This proved the right thing to do, because, – with the exception of one FGD with SWs that was postponed for a later date due to the lack of a required number of participants, – there were no disruptions in the schedule of the survey.

2 FGDs were conducted by a moderator in two languages, – Uzbek and Russian, – due to the mixed composition of the groups by their language preferences. Due to this, these FGDs lasted longer than the rest FGDs. All the other FGDs and IDIs were conducted in one language, and lasted, on average 1.5 hours.

The characteristic feature of the representativeness of FGD and IDI participants in this year survey as compared to the 2011 survey was that this year there were more representatives of respondents with traditionally Uzbek mentality.

#### Notes

**1) Correlation between women and men among the outreach workers:** approach 60% of men and 40% of women. The reasons for the less percent of women:

- men have more contacts among the target groups, including groups of women, since male outreach workers are more mobile;
- women are more preoccupied with their family problems and children; therefore they don't have enough time for outreach work.

**2) Functioning and closed NGOs in HIV/AIDS and tuberculosis:**

Within a year/half-a-year there was opened the *Intilish* NGO based on *Contact* NGOs (former Director of *Contact* Tatyana Sergeyevna set up the *Intilish* NGO). At that time, many NGOs started to be afraid of using manuals, handing out booklets, syringes and condoms, – so that it would not look like 'immoral propaganda of sexual behavior among youth'. The NGO *Ishonch va khayot* was closed but was recently reopened. It was closed due to the same reasons as the NGO *Contact*. According to the outreach workers, these are the main two NGOs that are working in this sphere. All the other NGOs discontinued their activities.

**3)** The respondents mentioned such places of receiving services as Trust Points and Anonymous Consulting Room. These are, actually, two names for one and the same facility. Trust Points were created under *World Vision* Project. After the sustainability of the Project was ensured *World Vision* officially handed over all the Trust Points to the state in 2011, – to rayonrayon Health Ministry departments, – and are now called Anonymous Consulting Rooms.

**4)** All in all, there were initially created 11 Trust Points in Tashkent (one in each rayon). However, in the first year of their activity, after they had been handed over by *World Vision* to the state (namely, under the jurisdiction of rayon HM departments), one of them (located at Farkhad Bazaar) was closed. According to an outreach worker, it was closed due to bureaucratic obstacles. Another factor for closing of this Trust Point was the fact that at that time, there were functioning 2

Trust Points in the territory of Chilanazar rayon (another one at the Republican AIDS Center). Now there is only this one Trust Point in Chilanazar.

5) Outreach workers of *USAID Dialogue on HIV and TB* Project and other NGOs were assigned to some Trust Points as volunteers. Outreach workers are inviting ‘clients’ there (this is how they themselves call them), and are providing practical assistance then there. Outreach workers are not being paid any salaries in these Trust Points, – they are only being paid under *Dialogue* Project.

## **QUESTIONNAIRES AND GUIDES FOR FGDS AND IN-DEPTH INTERVIEWS**

### **TRANSCRIPTS OF FGDS AND IN-DEPTH INTERVIEWS**